

**Understanding the lived experience of  
adult blood and marrow transplant patients in isolation  
via an art making task and verbal interview**

A Thesis

Submitted to the Faculty

Of

Drexel University

by

Carrie Adcock

in partial fulfillment of the

requirements for the degree

of

Master of Arts in Creative Arts in Therapy

May 2008

## **DEDICATIONS**

This thesis is dedicated to my family. Thank you for your support and encouragement through out this process. I love you all! Also, I would like to dedicate this thesis to my fiancé, Phil. Thank you for keeping me grounded and supporting me every step of the way. I love you.

## **ACKNOWLEDGEMENTS**

First, I would like to acknowledge all of the nurses and staff on the Blood and Marrow Transplant Unit for making my experience on the unit such a great one. Thank you Neal Flomenberg, MD, Joanne Filicko, MD, Matthew Carabasi, MD and Caroline Peterson, MA, ATR-BC, LPC for supporting me during my study. I would like to thank Florence Ierardi, MM, MT-BC, LPC for taking the time to be on my thesis committee and for her insight. Also, thank you Jan Taksa, MSW for your humor, kindness and encouragement on the blood and marrow transplant unit and during my thesis process. Finally, I would like to thank Elizabeth Hartzell Ph. D., ATR-BC, LPC for your endless encouragement, guidance and support.

## TABLE OF CONTENTS

DEDICATIONS.....	ii
ACKNOWLEDGEMENTS.....	iii
LIST OF TABLES.....	viii
LIST OF FIGURES.....	ix
ABSTRACT.....	x
I. INTRODUCTION.....	1
II. LITERATURE REVIEW	
Introduction.....	5
History and Demographics.....	5
The Treatment.....	6
Types of Transplants.....	9
Diseases Amenable To This Treatment.....	12
Precautions.....	12
Effects of Transplant.....	14
Physical.....	14
Psychological/ Psychosocial.....	15
Isolation.....	17
Financial Implications.....	23
Transplant Team.....	24
Importance of Caregivers/Family.....	25
Mental Health Interventions.....	26
Social Support.....	26

Support Groups.....	27
Alternatives Therapies.....	27
Art Therapy.....	28
Medical Art Therapy.....	29
Art Therapy In An Isolation Situation.....	30
Art Therapy With Adult BMT Patients.....	31
III. METHODOLOGY	
Design of Study.....	33
Location of the Study.....	34
Time Period for Study.....	34
Enrollment Information.....	34
Subject Type.....	34
Subject Source.....	34
Recruitment.....	34
Subject Inclusion Criteria.....	35
Subject Exclusion Criteria.....	35
Investigational Methods and Procedures.....	35
Informed Consent.....	37
Data Collection.....	38
Introduction.....	38
Art-making Directive.....	38
Closure Procedure.....	39
Data Analysis.....	39

Possible Risks and Discomforts to Subjects.....	41
Special Precautions to Minimize Risk or Hazards.....	41
IV. RESULTS	
Overview.....	42
Analysis of the Data.....	43
Textural Description of Participant 1.....	63
Textural Description of Participant 2.....	65
Imaginative Variation for Participant 1.....	68
Structural Description of Participant 1.....	69
Imaginative Variation for Participant 2.....	70
Structural Description of Participant 2.....	71
Composite Analysis of the Two Participants.....	74
Composite Textural Description.....	81
Composite Imaginative Variation.....	85
Synthesis of Composite Textural and Composite Structure Structural Descriptions.....	88
V. DISCUSSION	
Overview.....	91
Description of Major Themes from Verbal Interview.....	93
Description of the Artwork and Art Making Process.....	96
Possible Clinical Applications.....	98
Delimitations.....	99
Limitations.....	100

Future Research.....	100
VI. SUMMARY AND CONCLUSIONS.....	102
VII. LIST OF REFERENCES.....	104
VIII. APPENDICES	
Appendix 1: Recruitment Flyer.....	109
Appendix 2: Consent Form.....	110
Appendix 3: Transcribed Interviews.....	115

## LIST OF TABLES

Table 1.	Participant 1's Initial themes that developed from verbal statements about the experience of being a blood and marrow transplant (BMT) patient in isolation .....	46
Table 2	Participant 1's Themes and artistic characteristics developed during art-making task.....	51
Table 3	Participant 2's Initial themes that developed from verbal Statements about the experience of being a blood and marrow Transplant (BMT) patient is isolation.....	53
Table 4	Participant 2's Themes and artistic characteristics developed during art-making task.....	61
Table 5	Composite themes developed from verbal interview of the two participants.....	75
Table 6	Composite themes and artistic characteristics developed through the artwork of the two participants.....	80



**LIST OF FIGURES**

Figure 1.	Participant 1's Artwork 9 x 12 white paper. Marker.....	50
Figure 2.	Participant 2's Artwork 9 x 12 white paper. Marker and craypas.....	60

## **ABSTRACT**

Understanding the lived experience of adult blood and marrow transplant patients in isolation via an art making task and verbal interview

Carrie Adcock, BA

Dr. Elizabeth Hartzell, Ph. D., ATR-BC, LPC

Blood and marrow transplants are becoming more widely used to treat a variety of diseases. Because the number of individuals that are receiving transplants is expanding, it is important to increase knowledge of what the patients may experience. Two blood and marrow transplant patients in isolation consented to participate in the study. Both participants were female and were within the age range of 18 to 70.

Moustakas' phenomenological research method was used to investigate the overall experience of the participants. Data collection consisted of two parts: non-verbal (an art making task) and verbal (an in-depth verbal interview).

The study found that adult blood and marrow transplant patients in isolation are challenged mentally and physically. The artwork of the participants was analyzed the common themes found were: isolation/loneliness, anxiety, confinement, depression, need for control, dependence, isolation of affect frustration, transplant. The transcribed interviews of the participants were analyzed. Revised themes of the participants' experiences were as follows: transformation of self, feelings of invasion, anxieties about protective confinement, and loss of autonomy and acceptance of dependence.

Both patients were able to use the artwork as a non-verbal way of communicating their experience, as well as a reference tool during the verbal interview. The artwork appeared to be an effective tool to the patient to describe their experience. The findings

of this study may be used as an educational tool for medical staff, mental health staff, and blood and marrow transplant patients. The findings may increase empathy and understanding for adult blood and marrow transplant patients in isolation. Finally, the results could encourage future research.

## CHAPTER 1: INTRODUCTION

“More than 35,000 children and adults need transplants of stem cells within the bone marrow each year” (Twombly, 2006, pg. 2). If one is fortunate enough to receive a transplant before their illness results in death, there are negative effects that the transplant may cause, other than physical. “BMT (blood and marrow) involves potentially lethal doses of chemotherapy and frequently totally body irradiation (TBI), followed by a prolonged period of isolation while the transplanted marrow engrafts” (Jenkins & Alexander, 1994, pg. 1). The problem that the study addresses is that research has shown “such isolation was found to generate mild to pronounced feelings of loneliness, frustration, and emotional coldness, as well as significant psychological deprivation caused by not being able to touch anyone physically” (Steeves, 1992, pg. 900). Much of the research pertaining to the psychiatric and psychosocial effects of blood and marrow transplantation (BMT) “is nonempirical and consists of clinical observations, discussions of case histories, and suggestions of strategies for clinical management and intervention in the BMT setting” (Andrykowski, 1994, 14). There is a limited amount of research that uses verbal and non-verbal processes as a way for stem cell transplant or bone marrow transplant patients in isolation to communicate.

The purpose of my qualitative phenomenological study is to explore the lived experience of adult blood and marrow transplant patients in isolation via an art making task and an in depth interview. It is necessary to address this problem because there is a minimal amount of literature in general regarding art making and adult blood and marrow transplant patients in isolation. In fact, only two studies were found that researched the value of art therapy on adult bone marrow recipients in isolation.

Gabriel, Bromberg, Vandenvoorenkamp, Walka, Kornblith, & Luzzatto (2001) found that art therapy was used by the BMT patients to increase positive feelings, relieve suffering and helped patients understand their existential and spiritual issues. Greece (2003) also found that art therapy appeared to be a beneficial intervention for adult BMT patients in isolation. In her study, she claimed that art therapy provided psychosocial support in dealing with the experience of isolation and with the patient's disease.

This qualitative study would allow the BMT patient to express him/her self nonverbally through the artwork and verbally through an in depth interview. The information gathered would enable mental health professionals, physical health professionals, and art therapists to further understand a stem cell transplant patient's experience in isolation.

My research question is, what is the lived experience of adult blood and marrow transplant patients in isolation via art making task and an in depth interview? Moustakas (1994) quoted A.N. Whitehead, "that neither common sense nor science can proceed without the strict consideration of what is actual in experience" (pg. 44). Therefore, a qualitative research method, such as a phenomenological study will be more beneficial by "searching for meanings and essences of experience rather than measurements and explanations" (Moustakas, 1994, pg. 21).

This qualitative study consisted of two parts, an art therapy task and an in-depth interview. Two subjects participated in the study. The researcher met with each subject individually for one session. However, if the patient needed extra time, then the study took place during two meetings. During the session, the researcher asked each participant to create art based on her lived experience of being a BMT patient in isolation.

After the art intervention, the researcher asked each participant to describe his or her artwork and associations plus additional questions.

According to Moustakas (1994), “The phenomenological interview involves an informal, interactive process and utilizes open-ended comments and questions” (pg. 114). The researcher will ask each participant to describe their artwork that is based on their experience of being a stem cell transplant patient in isolation. Each interview will be recorded and transcribed. The transcriptions will be used to find “textural descriptions of the experience” (Moustakas, 1994, pg. 118). “From the textural descriptions, structural descriptions and an integration of textures and structures into the meanings and essences of the phenomenon are constructed” (Moustakas, 1994, pg. 118).

A patient may not only be challenged with physical side effects caused by the transplant. A blood and marrow transplant may cause psychological symptoms. According to The Leukemia & Lymphoma Society (2002), “The loss of autonomy, the isolation, the separation from work, school, friends, colleagues, and outside interests have to be endured...For most patients, the experience is psychologically challenging” (pg. 34). When describing bone marrow transplantation, Andrykowski (1994) describes the side effects as follows “anxiety, depression, withdrawal, anger and hostility, “survivor guilt,” noncompliance, sleep difficulties, anorexia, paranoia, and “acting out” (pg. 14).

The mental health and physical health professionals may benefit from this study because it would provide further understanding of what the experience of being a BMT patient in isolation is like with the additional information gained from the art experience.

A limitation to this study was that there were only approximately 12 patients on the hospital's BMT unit at any particular time. Not all patients were able to participate in the study because of various reasons (e.g. the patient was too sick).

A delimitation of this study was the small sample size ( $n = 2$  patients). In a qualitative research method, such as a phenomenological research, research is done by "focusing on the wholeness of experience rather than solely on its objects or parts" (Moustakas, 1994, pg. 21). Even though the sample size was small, the phenomenological research was beneficial by "searching for meanings and essences of experience rather than measurements and explanations." (Moustakas, 1994, pg. 21). Data collected was based on the overall experience of the participants. However, because there was small sample size, the data cannot hypothesize what the experience would be like for this particular population.

Even though there were limitations and delimitations to this qualitative study, it allowed the patients to express their experience in two ways: nonverbally (through the artwork production) as well as verbally (through the open-ended interview). The information gathered may enable mental health professionals and physical health professionals to further understand the lived experience of an adult BMT patient in isolation.

## CHAPTER 2: LITERATURE REVIEW

### *Introduction*

Blood and marrow transplants are becoming more widely used as a source of treatment for many diseases. An adult who undergoes a blood and marrow transplant (BMT) may face many challenges, one of which is isolation. An adult blood and marrow transplant (BMT) patient may feel many negative psychological effects while in isolation. However, there are few studies that use art as a way for adult BMT patients to nonverbally express their experience of being a blood and marrow patient in isolation. Further investigating needs to be done exploring the use of non-verbal communication (art-making) and verbal communication (in depth interview) with adult BMT patients in isolation in order to fully understand their experience during this challenging time.

### *History and Demographics*

Blood and marrow transplantation is an advanced procedure that has developed over the past few decades. According to The Leukemia & Lymphoma Society (2002), marrow transplantation became a treatment option to people who were exposed to radiation after World War II.

The first successful bone marrow transplant performed on a human was done in 1957 (Andrykowski, 1994, pg. 13). “Until about 10 years ago, marrow transplants were considered experimental procedures to be used only for severely ill patients. Now they are considered the therapy of choice for several diseases” (Thomas, 1987, pg. 291).

According to the Center for International Blood and Marrow Transplant Research (CIBMTR, 2008), “There are an estimated 50-60,000 hematopoietic stem cell transplants (HCTs) done annually worldwide.” The Leukemia and Lymphoma Society (2002)



quoted the CIBMTR in their informational booklet for patients when stating, “An estimated 16,000 people in North America had autologous or allogeneic stem cell transplantation for blood cancers in 2003, the most current data available” (pg.2).

“Although BMTs now save thousands of lives each year, 70 percent (of people needing a transplant) are unable to have one because a suitable bone marrow donor cannot be found” (Columbia Presbyterian Medical Center 2007, pg.2). Today, there is a major shortage of donors. It is not uncommon for a BMT patient to die while waiting for a donor.

### *The Treatment*

A blood and marrow transplant is needed “when a person’s bone marrow has been damaged or destroyed due to a disease or intense treatments of radiation or chemotherapy for cancer” (Thomas Jefferson University Hospital, 2007, pg. 1). “The immature or defective blood cells interfere with the production of normal blood cells, accumulate in the bloodstream and may invade other tissues” (Columbia Presbyterian Medical Center, 2007, pg. 3).

In order to understand what a blood and marrow transplant is, one must know what bone marrow is. According to Thomas Jefferson University Hospital (2007), “Bone marrow is the soft, spongy tissue found inside bones. It is the medium for development and storage of about 95 % of the body’s blood cells” (pg. 1). There are three different types of cells. Columbia Presbyterian Medical Center (2007) explained the functions of the three types of blood cells as follows:

These blood cells include white blood cells (leukocytes), which fight infection; red blood cells (erythrocytes), which carry oxygen to and remove waste products from organs and tissues; and platelets, which enable the blood to clot ( pg. 2).

Bone marrow that is needed for transplant is located in the breastbone, skull, hips, ribs and spine. These particular locations are significant to the BMT process because it is these locations that contain the stem cells. (Columbia Presbyterian Medical Center, 2007). Stem cells are immature blood cells that develop into any type of blood cell that the body needs to function (University of Utah Health Sciences Center, 2003)

Recently researchers have discovered patients may use stem cells from their bloodstream and/or bone marrow for transplantation. There is 1/100 number of stem cells in the blood stream when compared to the number of stem cells in marrow. (Thomas Jefferson University, 2001).

“Since blood and marrow are both good sources of stem cells for transplantation, the term ‘stem cell transplantation’ has replaced ‘bone marrow transplantation’ as the general term for this procedure” (The Leukemia & Lymphoma Society, 2002, pg. 3). Even though the name differs slightly, “the patient undergoes all other activities, complications or side effects, and recovery period that are involved in traditional bone marrow transplantation” (Thomas Jefferson University Hospital, 2007).

Patient undergoing an allogeneic transplant (when a patient receives stem cells from a donor) receive high doses of chemotherapy and/or radiation therapy before the BMT. The difference between chemotherapy and radiation therapy is chemotherapy utilizes drugs to destroy cancer cells, while radiation therapy (radio-therapy) uses high-

energy rays (the Cancer.net, 2007, pg. 1). These procedures are also referred to as “conditioning.” Patients undergoing an autologous transplant receive intensive cytotoxic therapy to kill off the cancerous cells before transplant. The following description explains why patients receiving an autologous transplant do not go through conditioning:

Autologous blood or marrow transplantation (when a patient receives their own stem cells) does not carry the risk of either graft rejection or graft versus host disease and thus does not require conditioning treatment or immunosuppressive treatment. However, the patient does receive very intensive cytotoxic therapy to kill residual leukemia, lymphoma or myeloma cells. The autologous stem cells are used to restore blood cell production, thereby making chemotherapy and radiation therapy tolerable (The Leukemia & Lymphoma Society, 2002, pg. 21). These treatments not only destroy cancerous cells, but normal cells as well. A transplant helps replace the cells and produces new ones. The process in which the cells start to produce new healthy cells is called engraftment. Once the blood counts reach a certain level, the doctors know that the transplanted stem cells have taken over the patient’s body. However, if complications occur (ex. Infections), this may delay the engraftment process. It may take months or years for the immune system to restore.

Stem cells necessary for transplant are collected in two different ways. When collected through the bone marrow, a procedure called harvesting occurs. During harvesting, the donor is under general anesthesia. A needle is inserted several times into the marrow of the bone and collects the stem cells. “The amount of bone marrow harvested depends on the size of the patient and the concentration of bone marrow cells in the donor’s blood” (Columbia Presbyterian Medical Center, 2007, pg. 8).

Another process that is used to collect stem cells is called apheresis. During this process, stem cells are collected from circulating cells in the donor's blood (the peripheral system), not the marrow. The cells are collected through a needle connected to one arm of the patient, filtered through a special machine, and the remaining blood and plasma go back in the patient through the other arm. It may take many sessions of collecting stem cells through the bloodstream in order to collect enough stem cells. (Thomas Jefferson University Hospital, 2007).

### *Types of Transplants*

There are three different types of BMT procedures: autologous bone marrow transplant, allogeneic bone marrow transplant, and umbilical cord blood transplant. An autologous BMT is when patients are their own donors. An autologous transplant is an option for a BMT patient "if the disease afflicting the bone marrow is in remission or if the condition being treated does not involved the bone marrow" (Columbia Presbyterian Medical Center, 2007, pg. 5). The patient receives their cells intravenously in their hospital room. The patient is awake during the non-surgical procedure.

An allogeneic BMT procedure is when a patient receives cells from a donor. The genetic makeup of the donor's marrow must match the patient's genetic makeup as closely as possible. Compatibility is based on blood tests. The patient may receive marrow from an identical twin (which is called a syngeneic transplant), a related donor or an unrelated donor.

When a patient receives stem cells from an identical twin, they are considered an identical match. Having an identical match has positive and negative aspects. "With this type of transplant, donor cells are not rejected and the recipient's tissues are not attacked

by the donor's immune cells (lymphocytes)" (The Leukemia & Lymphoma Society, 2002, pg. 20). A syngeneic transplant may not benefit the patient because the genetic makeup is too similar. The cells that are transplanted may not recognize any remaining cancerous cells that should be killed because the genetic make-up is too similar (Non Hodgkin's Lymphoma Cyberfamily, 2006).

A patient can receive stem cells through a related donor. During this allogeneic transplant, the donor's cells closely match the related patient. "The donor who has the potential to match the prospective recipient most closely is the sibling of the patient, since both received their genetic composition from the same parents" (The Leukemia & Lymphoma Society, 2002, pg. 20). If the patient has siblings, the chances of a complete match are 35% (Columbia Presbyterian Medical Center, 2007). When the donor is the patient's parent, "the genetic match is at least half identical to the recipient" (Thomas Jefferson University Hospital, 2007, pg. 1). This is referred to as a haploid-identical match.

Until recently, patients who were older (55 and above) or had poor health were not good candidates for allogeneic transplants. The reason for this is because the pre-transplant treatment was too intense. As an alternative, nonmyeloablative transplantation (mini-transplant) is done. "A nonmyeloablative transplant is one that does not completely destroy the patient's diseased marrow. Patients being prepared for a nonmyeloablative transplant receive much lower doses of conditioning" (The Leukemia & Lymphoma Society, 2002, pgs. 30). According to The Leukemia & Lymphoma Society (2002), "The effectiveness of nonmyeloablative transplants depends on a reaction called graft versus malignancy (GVM), in which the recipient's new immune system

(originating from the donated stem cells) may destroy the bulk of remaining cancer cells” (pg. 30).

The final allogeneic transplant donor option is from an unrelated donor, “the genetically matched marrow or stem cells are from an unrelated donor. Unrelated donors are found through the national bone marrow registries” (Thomas Jefferson University Hospital, 2007, pg. 1). This type of donor is called an unrelated bone marrow transplant (UBMT) or MUD (matched unrelated donor). According to a source affiliated with the large University Hospital (where this study took place), there are more donors willing to give stem cells because they can be received by giving blood. However, there is still a shortage of donors.

An umbilical cord blood transplant is the final option for a BMT. Doctors have discovered that there are many stem cells in an umbilical cord. The stem cells are taken from the umbilical cord after birth and transplanted.

### *Risks*

Blood and marrow transplantation is a highly risky procedure. A patient may have complications depending on what type of transplant she or he receives.

During an autologous transplant, there is a risk that a patient will be receive cancerous cells back into their system. “To avoid this, the marrow may be treated to rid it of cancer cells after it is harvested and before it is frozen” (The Leukemia & Lymphoma Society, 2002, pg. 22). This procedure is called “purging” the cancer cells.

During an allogeneic transplant (not including syngeneic transplantation), a patient may have the following complications: host versus graft effect or graft versus host disease. Host versus graft effect is when the recipient’s immune system rejects the

donated stem cells. Through conditioning (when the patient's immune system is suppressed) host versus graft effect can be prevented.

“Graft versus host disease (GVHD) is a condition in which the transplanted donor marrow or blood stem cells attack the patient's body.” (The Leukemia & Lymphoma Society, 2002, pg. 27). There are two different types of GVHD, acute GVHD and chronic GVHD. Both types are life-threatening. Acute GVHD occurs within 90 days of transplantation and chronic GVHD occurs after three months of transplantation. GVHD is prevented or minimized with the administration of anti-cell rejection medications.

#### *Diseases Amenable To This Treatment*

More diseases are being treated with the BMT procedure everyday. The following excerpt from Seattle Cancer Care Alliance (2006) states the diseases bone marrow transplants are able to treat:

Today, bone marrow transplants are used to treat cancers and other diseases, including aplastic anemia, sickle cell anemia, immune deficiency disorders, and autoimmune diseases such as scleroderma and multiple sclerosis. Malignant diseases (cancers) treated with transplantation include acute and chronic leukemias, Hodgkin's disease and non-Hodgkin's lymphoma, myelodysplasia, multiple myeloma, myelofibrosis, and renal cell carcinoma (pg. 2).

#### *Precautions*

After the transplant, patients are not free to leave the hospital. “Patient management in transplantation involves providing complex care for severely ill and immunocompromised patients” (Cohen, Ley, Tarzian, 2001, pg. 592). The conditioning

and transplant causes the patients' blood counts to lower. The white blood cells (fight infection) are very low at this point, causing the patients to be prone to infection. When the white blood cells are low during this phase of the treatment, the patient is considered to be neutropenic (The Leukemia & Lymphoma Society, 2002). In order to protect the patients from infection during the neutropenic phase, they must stay in an isolative setting in the hospital.

The degree of isolation varies between units. "These vary from a total protective environment, including rooms with laminar airflow, to strict or simple protective isolation environments" (Cohen, Ley, Tarzian, 2001, pg. 593). Medical staff and visitors must be aware of specific precautions to decrease the patients' chances of contracting an infection. Such precautions are as follows: constantly washing their hands and wearing protective garb (eg. gown(s), masks and gloves). When the patient leaves the unit, s/he must wear a mask to avoid germs. If the patient is not cautious, a low-grade fever could be deadly.

There is no way of knowing when and if a patient will be able to leave the isolation setting. "Although four to five weeks is the minimum stay, complications can develop that can extend hospitalization to 100 or more days" (Andrykowski, 1994, pg. 14). During this time, the patient is given many antibiotics and blood transfusions during this time to prevent infection. If complications do not occur, the blood counts increase and engraftment (when donated cells start to produce new healthy cells) occurs. However, if complications (ex. Pain, fever, infection, GVHD, or) occurs, discharge may be delayed. Even when a patient does get discharged, "The patient will require attentive follow-up care for two to three months after discharge from the hospital. It may take six



months to a year for the immune system to fully recover from this procedure” (Medline Plus, 2007, pg. 5).

The amount of time spent in isolation can be very challenging on an adult patient physically, psychologically and economically. According to Andrykowski (1994), “A growing body of literature is addressing the psychiatric and psychosocial aspects of BMT. Much of this literature is nonempirical and consists of clinical observations, discussions of case histories, and suggestions of strategies for clinical management and intervention in the BMT setting” (pg. 14). “However, a relatively neglected area of research is the concomitant social isolation experience by BMT patients” (Cohen, Ley, Tarzian, 2001, pg. 593).

### *Effects of Transplant*

#### *Physical*

A patient that undergoes the BMT procedure will likely feel significant physical side effects. The chemotherapy and/or radiation treatments prior to transplant may cause a patient to feel extremely weak, tired, and nauseated. Campbell (1999) claimed “Suffering chemotherapy is associated with experiencing the toxicities of high-dose chemotherapy, including nausea, anorexia, mucositis, poor memory and lethargy (pg. 444).

The transplant may cause a patient to experience flu-like symptoms for weeks (e.g. vomiting, diarrhea and a decrease in appetite). “Walking, sitting up in bed for long periods of time, reading books, talking on the phone, visiting with friends or even watching TV may require more energy than the patient has to spare” (Columbia

Presbyterian Medical Center, 2007, pg. 13). A patient's appearance may change as well including, hair loss, darkening of the skin, itchy/ dry skin, mouth and lip sores.

*Psychological/ Psychosocial*

An adult who receives a BMT may face many psychological and psychosocial challenges. According to Blood & Marrow Transplant Newsletter (1993), "While most pain is caused by physical problems, the degree of suffering associated with the pain is closely linked to psychological, social and environmental pressures on the patient."

Andrykowski (1994) states, "many BMT patients exhibit a variety of stress-induced responses, including anxiety, depression, withdrawal, anger and hostility, 'survivor guilt', noncompliance, sleep difficulties, anorexia, paranoia, and "acting out." Family members of BMT recipients are also at risk for stress-related reactions" (pg. 14).

Studies show that patients may experience feelings related to mortality and death (Thain and Gibbon, 1996). This is understandable considering that the procedure is risky. "For example, projected five-year survival rates of only 50%-60% have been reported for adults receiving allogeneic BMT during first remission for leukemia" (Andrykowski, 1994, pg. 14). Not only is the procedure long and possibly painful, it is not guaranteed that the patient will survive.

Unlike children who have this procedure done, adults may have a difficult time with dependent relationships with the medical staff and caregivers. Patients may experience feelings of helplessness, anger or resentment during this time. "For many, it's unnerving to be totally dependent on strangers for survival, no matter how competent they may be" (Columbia Presbyterian Medical Center, 2007, pg. 15). Many patients need help doing daily activities like showering or using the bathroom.

According to Andrykowski (1994), “Some evidence suggests that BMT recipients are at risk for developing symptoms indicative of neurological or central nervous system (CNS) toxicity, for example, seizures, visual hallucinations, CNS and neurological complications, or neuropsychological impairment” (pg. 17). It is not uncommon for a BMT patient to have temporary mental confusion due to so many different types of drugs that are given. Columbia Presbyterian Medical Center (2007) states, “Temporary mental confusion sometimes occurs and can be quite frightening for the patient who may not realize it’s only temporary” (pg.14).

Sexuality is another psychological factor a patient may have to deal with. Patients may not feel sexual for many reasons. They feel physically ill due to side effects from the BMT or complications caused by the BMT (e.g. weakness or GVHD) and their appearance (e.g. loss of hair). “Most patients are sterile after BMT; this loss of reproductive capacity has a potentially profound effect on sexuality, self-esteem, and social behavior” (Andrykowski, 19, 1994). Molassiotis (1997) further explains the effect of sexuality on a BMT patients as follows:

...BMT patients face permanent dysfunction (e.g. infertility or induced menopause) in the early years (and probably the most productive ones) of their lives, producing intrapersonal conflict unlikely to be resolved by the support of family members (pg. 323-324).

Male patients have the option of banking their sperm before the BMT process. This way, their sperm can be used for fertilization with their partner when the male patients are sterile after the procedure. However, Holland et al. (1977) claimed that “sexual

expression became less important but affection expressed by physical closeness became more important” while going through the BMT process (pg. 878).

According to Thain and Gibbon (1996), many studies have been done that predict a pattern of psychological reactions and patient responses to specific stressors throughout the BMT process. Haberman (1988), cited by Thain and Gibbon (1996), developed six stages of the BMT process that patients go through, each with psychosocial reactions and behaviors. However, it is important to note, “Patients may not exhibit all responses, and they may not appear in exact order; responses may be transitory or persistent” (pg. 529).

### *Isolation*

As mentioned previously, isolation is major part in the BMT process. Because the patient is immune suppressed, it is crucial that the patient is in an isolative setting to decrease the chance of contracting a disease. For some patients, the time in isolation may be challenging. Folsom and Popkin (1987) were cited by Thain and Gibbon (1996) when they described the isolation period as an “emotional roller coaster.” Researching this topic may illuminate patients’ perceptions of isolation due to the necessity of this condition in treatment. Collins et al. (1989) referred to a study done by Nehenkis, Gerber & Charter (1984) which claimed that staff misperceptions of the patients may do harm to the patients.

According to Collins, Upright and Aleksich (1989) there are three different types of isolative environments. These environments are described as follows:

...the *life island*, a plastic tent enclosing the patient’s bed; the laminar air flow room that attempts to produce a sterile environment by filtering the air; and the

reverse isolation room in which staff and visitors wash their hands and put on a gown and mask upon entry (pg. 675).

It is important to note that there are two types or ways to provide isolation: protective or reverse isolation and source isolation. Protective or reverse isolation is an environment that protects the patient from contracting a disease. (Gammon 1999, Gaskill, Henderson, Fraser, 1997) Source isolation is when visitors or medical staff are being protected from catching the patient's disease (Gammon 1999, Gaskill, Henderson, Fraser, 1997). Knowles (1993) stated that it is important to note that the experience of isolation differs in each setting because "Patients in protective isolation are significantly involved in the decision to be isolated and are able to prepare for the experience over a period of time..." (pg. 53).

There are studies that have explored the experience of isolation (Cohen, Ley, Tarzian 2001, Collins, Upright, & Aleksich, 1989, Holland, Plumb, Yates, et al., 1977, Kellerman, Rigler, & Siegel, 1977, Knowles, 1993, Gaskill, Henderson & Fraser, 1997, Thain & Gibbon, 1996, Zerbe, Parkerson, & Spitzer, 1994). The results of these studies vary. Differences among studies could be due to the type of isolation explored in the study. Isolation affected the participants mentally and physically in most studies.

However, in some cases, patients were affected minimally during isolation.

Some studies claimed that the physical illness that patients encounter is more significant than the isolative setting (Campbell, 1999, Collins, et al., 1989, Holland et al. 1977, Lesko, Kern, & Hawkins, 1984 as cited by Collins, et al. 1989, Wilkins, Ellis, Dunbar & Gibbs, 1987, Zerbe, et al., 1994). Zerbe, et al. (1994) explained that patients viewed isolation as more of a provisional inconvenience than a stressor. Holland, et al.

(1977) found that psychological statuses of patients in isolation were affected when their physical illness worsened. Important days to the patients (ex. Anniversaries) impacted the patient, but not too significantly.

A negative psychological effect that patients may feel during isolation is frustration (Collins et al. 1989, Thain and Gibbon 1996). A feeling of frustration may be due to a prolonged time in isolation (Thain and Gibbon 1996), when a patient is close to discharge (Collins et al. 1989) or when a patient is longing to be apart of the world outside of their isolative setting (Thain and Gibbon 1996).

Another stressor caused by isolation is the sense of loneliness (Campbell, 1999, Holland, et al., 1977, Cohen, Ley and Tarzian 2001, Wilkins, et al., 1987) or abandonment (Cohen, Ley and Tarzian 2001, Thain and Gibbon 1996). In a source isolation setting, the loss of human touch negatively influenced some of the patients causing feelings of loneliness and distance (Holland, Plumb, Yates, et al., 1977). Even in a protective isolation setting, close personal contact is hindered due to risk of infection (Campbell, 1999). In a protective isolation setting, patients expressed “the possibility of being left alone was very stressful, describing this as ‘frightening’ and may be attributed to a sense of abandonment” (Thain and Gibbon, 1996, pg. 533). Because of physical barriers in isolation, patients may feel they have limited social contact (Grazier, 1988, Knowles, 1993), which may promote negative feelings.

The findings of Knowles (1993) were consistent with Thain and Gibbon (1996) in that feelings of neglect and isolation were felt by patients in a source isolation unit.

These feelings were caused when the nurses would not respond quickly enough to the call

bell of the patients or by feeling “stigmatized” as a patient that needed to be in source isolation due to his contagious disease (Knowles, 1993).

Isolated BMT patients are challenged mentally as well as physically. Gammon’s (1999) literature study supported this statement. He stated that negative psychological effects were found in isolated patients. Kellerman et al. (1977) found that patients in isolation experienced many psychological effects such as, anxiety, depression, irregular sleep, withdraw, disorientation to time, regression and hallucinations. While waiting for their blood counts to rise, patients may feel anxiety because of doubts about whether they made the right decision to go through with a BMT (Haberman 1988 as cited by Thain and Gibbon 1996).

Sasaki, Akaho, Sakamaki, Akiyama, Yoshino, Hagiya, & Atsumi (2000) found that the most common disorders detected among BMT patients while in isolation were adjustment disorders, with anxiety and/or depression. It is important to note that the majority of mental disturbances improved before the isolation period was over.

Patients have perceived the physical isolation positively and negatively. Some patients accepted the isolation because they understood the reasoning behind it (Campbell, 1999, Collins, et al. 1989, Thain and Gibbon 1996). Some patients enjoyed being by themselves (Campbell, 1999) or felt lucky when comparing their progress to others during the BMT or being fortunate to have a donor (Thain and Gibbon, 1996). Other studies indicated that patients were conscious of germs and avoiding germs (Campbell, 1999, Cohen, Ley, & Tarzian 2001, Gaskill, Henderson and Fraser, 1997, Knowles 1993). Cohen, Ley & Tarzian (2001) found that participants wanted to protect

their family from seeing them in a weakened state or they wanted to protect them from exposure to infection. This influenced some patients to chose to be alone.

Other patients have described the isolative setting as a prison or inducing feelings of claustrophobia (Thain and Gibbon 1996, ). Feelings of confinement, imprisonment, and/ or feeling shut in were acknowledged (Campbell, 1999, Cohen, Ley and Tarzian 2001, Collins, et al., Knowles, 1993). Collins et al. (1989) claimed that patients felt more restricted by their IV tubing than the physical space of their room.

The protective clothing (ex. Masks, gloves, and gowns) that must be worn by visitors is another factor of isolation that has varied responses from patients. Collins et al. (1999) found that the protective clothing did not effect communication. Knowles (1993) noted that the protective clothing is more time-consuming, taking the nurses longer to get to the patient. Generally in this study, patients did not like the masks because the patients cold not see facial expressions. The following description is a statement from a patient in Knowles (1993) who felt stigmatized by the protective garb:

Everybody is wearing masks around you and you don't know why they're wearing them.. You don't even know what's wrong with you. You think it's something worse that you might have. It makes you feel isolated. I mean that's what you are, but it makes you *think* you are isolated (pg. 56).

It is apparent that some patients feel that the protective clothing is more distressing than others.

It was also found that some patients were hesitant to ask for help because they did not want to burden the nurses (Cohen, Ley & Tarzian 2001). Knowles (1993) found similar responses from patients. A patient commented, "Then they have to put the masks



on, so you don't want to trouble them so much. You have to think of everything that you might need at the time" (Knowles, 1993, pg. 54). When patients feel that they are burdening the nurses, this may be putting their physical well-being at risk (Cohen, Ley & Tarzian, 2001).

Along with physical isolation, patients may feel emotional isolation (Cohen, Ley and Tarzian 2001). In a study done by Cohen, Ley and Tarzian (2001) some patients felt that medical staff, family and friends did not fully understand their experience. Knowles (1993) found that nurses tended to avoid patients that were depressed because they felt they were not trained to meet their psychosocial needs.

Patients may cope with isolation in different ways. Nurses can help patients maintain a sense of control by providing choice. "Simple choices, like furniture placement, open or closed blinds, time of bathing or dressing change, and time of rising or settling" are different ways medical staff support a patient's sense of control in an isolative setting (Collins et al., 1989, pg. 678). Respondents from a study on the psychological effects of protective isolation, suggested different methods to help patients adjust psychologically to isolation (e.g. Access to calendars and window views to prevent disorientation to time) (Kellerman, et al., 1977).

Some patients felt bored (Cohen, Ley and Tarzian 2001, Knowles, 1993). Activities that patients may do to pass the time while in isolation are watch TV, clean their rooms, sleep, listen to the radio, talk with visitors. It is evident that visitors are important in the BMT process to alleviate the lack of human contact.

Caregivers and family play a huge role while the BMT patient is in the isolation setting (Campbell, 1999, Cohen, Ley and Tarzian 2001, Collins et al, 1989, Gaskill,

Henderson, Fraser, 1997 and Thain and Gibbon, 1996). Thain and Gibbon (1996) found that most patients acknowledged the importance of family, particularly their spouses. Collins et al. (1989) stated that two subjects in their study noted that “visits (are) the most critical factor in coping with isolation” (pg. 677).

A fear of leaving the isolation environment (Brown & Kelly 1976 as cited by Thain and Gibbon 1996, Haberman 1988 as cited by Thain and Gibbon 1996, Holland et al., 1977, Gaskill, Henderson, Fraser, 1997, Thain and Gibbon 1996) is also a stressor for patients. Even when patients' blood counts are at a safe level, they may still feel susceptible to infection (Holland et al. 1977).

Even when a patient is able to leave the hospital, the patient will either go to a long term care facility or be confined in their home. For many patients, this protracted stay means separation from friends and family member during a stressful time” (Thomas, 1987, pg. 300). The patient is instructed not to go out in crowded places or use public transportation, however if they must go out, she or he must wear a mask and is advised to go at a time that is less crowded.

### *Financial Implications*

The BMT procedure is an expensive procedure. If the BMT recipient is the family income provider, it may mean that less money is coming into the household. Therefore, a BMT procedure may cause financial stress on the family.

“Although most major insurance carriers now recognize transplantation as an accepted form of therapy, many patients have already exhausted their coverage by the time they receive the transplant” (Thomas, 1987, pg. 300). The average cost of a BMT is \$100,000.00. The expense is due to the days spent in the hospital, medication and

medical staff required to treat the patient. Even after the procedure, the patient needs to stay near the hospital to come in for frequent checkups and/or medications. It is not uncommon for a patient to live in a long-term recovery center near the hospital after leaving the isolation unit.

Due to the cost of the procedure, there is an “increasing concern regarding optimization of society’s investment in healthcare that is likely to result in greater emphasis on identification of BMT candidates who are more likely to be long-term survivors and have a reasonable quality of life (QOL) after BMT” (Andrykowski, 1994, pg. 15). Many studies have shown that patients’ QOL increases after the BMT procedure.

#### *Transplant Team*

The people that are needed to help treat a BMT patient is referred to as the transplant team. Thomas Jefferson University (2007) describes each role of the transplant team on their website as follows:

- Physicians – physicians who specialize in oncology, hematology, immunology, and bone marrow transplantation.
- Bone marrow transplant nurse coordinator – a nurse who organizes all aspects of care provided before and after the transplant. The nurse coordinator will provide patient education, and coordinates the diagnostic testing and follow-up care.
- Social workers – professionals who will help your family deal with many issues that may arise, including lodging and transportation, finances, and legal issues.
- Dietitians – professionals who will help you meet your nutritional needs before and after the transplant. They will work closely with you and your family.

- Physical therapists – professionals who will help you become strong and independent with movement and endurance after the transplantation.
  - Pastoral care – chaplains who provide spiritual care and support.
  - Other team members – several other team members will evaluate you before transplantation and will provide follow-up care as needed. These include, but are not limited to, the following: pharmacists, respiratory therapists, lab technicians, infectious disease specialists, dermatologists, gastroenterologists, psychologists.
- (pg. 2)

Many studies noted the importance of the nursing staff (Campbell 1999, Cohen, Ley and Tarzian 2001, Gaskill, Henderson, and Fraser 1997, Holland et al. 1977, Knowles 1993, Molassiotis, Van Ded Akker, & Boughton, 1997, Thain and Gibbon 1996). According to Campbell (1999), patients within the study “described nurses ‘encouraging’ and ‘giving a push in the right direction’ as a nurturing hope, a process which made them feel supported in their fight against cancer” (pg. 443).

#### *Importance of Caregivers/Family*

A caregiver tends to the needs of a patient receiving a transplant. This person may be a family member, close friend, or spouse. The role of a caregiver was described by Compton, McDonald, & Stetz (1996) as follows:

Caregivers typically leave their homes and communities to be with the patient at the treatment center, where they will live for up to four months.

Caregivers accompany the patient through the pretransplant phase...They attend classes and receive instructions that prepare them for caregiving at home...

Caregivers provide emotional support to the patient during conditioning therapy,

during the infusion of marrow cells, and while patients wait for marrow to engraft (pg. 1429).

It is evident that being a caregiver is highly time consuming and may affect the caregiver emotionally.

Caregivers of BMT patients face many different challenges when taking care of a BMT patient. Cohen, Ley and Tarzian (2001) concluded their study by stating the importance of educating caretakers. An adult BMT patient will not be able to continue their role in the family immediately after discharge from the hospital. The patient will not be able to work and will feel very weak.

It is necessary for caregivers to educate themselves on precautions to take and what to expect after the BMT patient arrives home. Cohen, Ley and Tarzian (2001) states, "The need to involve (the) family in teaching is critical both because it has been neglected and because the length of hospital stays continues to decrease" (pg. 607). If caregiver does not provide the patient with a clean and healthy environment, the patient could become severely ill again.

### *Mental Health Interventions*

When an adult makes the decision to have a transplant, she or he may feel a significant amount of distress. When going through the process, the patient may feel physical and mental deterioration. To help cope with these symptoms, many patients will seek different types of support.

### *Social Support*

It was stated earlier that family support is very significant in the BMT process. Syrjala, et al. (1993) as cited by Molassiotis et al. (1997) findings are consistent within

this statement when stating that “family relationship were important determinants of physical and psychological recovery in allogeneic BMT patients” (pg. 318). Molassiotis (1997) explained the importance of social support as follows, “The degree of functional support will determine the distance between the patient and the stressor-producing stimuli; the more the social support the greater the distance will be [between the patient and the stressor]” (pg. 323).

### *Support Groups*

Some patients found it helpful to talk to survivors of a transplant (Cohen, Ley, & Tarzian 2001). It is important to refer patients to groups that will meet their needs. Giese-Davis et al. (1999) as cited by Cohen, Ley & Tarzian (2001) described the factors that are most valued by cancer patients in support groups as follows:

...increasing social contact, developing a new attitude, expressing true feelings, getting support and encouragement, increasing access to resources, and discussing sexuality (pg. 606).

Also, because it is possible to develop mental disturbances during the isolation period, Sasaki et al. (2000) emphasize the significance of psychiatric interventions during this time. In the study done by Dunkel-Schetter (1984) cited by Cohen, Ley & Tarzian (2001), health care professionals appeared to offer more support when offering information and emotional support to patients than did family and friends who would provide information support.

### *Alternative Therapies*

It has been found that many non-drug therapies may help patients cope with their transplant situation. “They include education, positive coping statements, distraction,

relaxation, imagery, hypnosis, application of heat or cold to the affected area, massage and exercise” (Blood & Marrow Transplant Newsletter, 1993, pg. 3). These alternative non-drug therapies may help decrease the patient’s anxieties and help patient cope with their pain.

### *Art Therapy*

Art therapy is an alternative therapy that may be effective for many different populations, including adult BMT patients in isolation. American Art Therapy Association (2008) defines art therapy as follows:

Art therapy is the therapeutic use of art making, within a professional relationship, by people who experience illness, trauma, or challenges in living, and by people who seek personal development. Through creating art and reflecting on the art products and processes, people can increase awareness of self and others, cope with symptoms, stress, and traumatic experiences; enhance cognitive abilities; and enjoy the life-affirming pleasures of making art.

Rubin (2001) explains the significance of art therapy as follows, “...art is concrete and visual, in addition to its value in *uncovering* unconscious imagery and *discovering* unconscious fantasies and impulses” (pg. 25). Unlike traditional verbal therapy, art therapy offers a permanent concrete non-verbal way of expressing oneself.

Naumberg (1987) states, “the processs of dynamically oriented art therapy is based on the recognition that man’s fundamental thoughts and feelings are derived from the unconscious and often reach expression in images rather than in words” (pg. 1). Because thoughts are put into images before words, the artwork can be seen as an

advantage. During art therapy, a client is able to express him/her self two ways: verbally (through talking) and non-verbally (through the images).

Wadeson (1995) describes the benefits of art therapy as follows:

Expression in art stimulates fantasy, creativity, spontaneous unconscious imagery.

It offers the possibility of creating a self-reflection, an image of oneself and one's world, from which it is possible to separate to gain distance. In this way the art object may provide a unique self-confrontation and perspective

(pg. 1).

The artwork becomes a very powerful therapeutic tool that helps express the patients' unconscious and conscious emotions, thoughts and concerns.

#### *Medical Art Therapy*

Art therapy is increasing in scope and number in the medical setting. Malchiodi (1999) referenced her earlier work in an article when she defined medical art therapy as the "specialized use of art expression and imagery with individuals who are physically ill, experiencing trauma to the body, or undergoing aggressive medical treatment such as surgery or chemotherapy" (pg. 1). For cancer patients, it may be difficult to verbalize their emotion. "It is the art itself that provides a vehicle for expression, aided by the actual physical movement of artistic materials" (Nainis, et al. 2006, pg. 163.).

The goal of medical art therapy is to increase the quality of life and "the greatest challenge is the attempt to integrate somatic, psychological and existential themes such as pain, loss, and death" (Luzzatto & Gabriel, 1998, pg. 745). Malchiodi (1999) referenced the C. W. Koop Center (1998) that stated the art programs in hospitals "provide many benefits including reduction of stress, increased capacity to communicate feelings about



symptoms, and improvement of blood pressure, heart rate, and respiration through exposure to the arts” (pg. 3).

### *Art Therapy In An Isolation Situation*

According to Rosner David and Illusorio (1995), “Patients benefit from the artistic expression of their emotions not only regarding the disease and prognosis, but also regarding the unique experience of isolation...Participation in art therapy serves to decrease anxiety and to provide an opportunity to exercise control” (pg. 207). This study by Rosner David and Illusorio determined that art therapy was an effective coping tool for adults in isolation.

Luzzatto and Gabriel (1998) described the importance of art therapy in an isolation setting as follows:

Isolation involves loss of control, loss of relationships, anxiety and anger: participation in art therapy provides an opportunity for the patients to exercise control, choice and criticism, with a general decrease in anxiety (pg. 747).

Art therapy has also been used in other isolative settings. As cited by Gabriel et al. (2001), art therapy has been used in a burn trauma unit (Appleton 1993) and with hospitalized cancer patients (Conel, 1992, 1998; Councill, 1993; Prager, 1995; Malchiodi, 1998, 1999; Pratt and Wood, 1998). Another study that proved art therapy was effective with cancer patients was done by Bar-Sela, et al. (in press). This study indicated that cancer patient’s depressive symptoms decreased, along with fatigue. Because of the success of art therapy with these settings, Gabriel et al. (2001)

hypothesized that art therapy would be an appropriate intervention for adult BMT patients in isolation.

#### *Art Therapy With Adult BMT Patients*

Current research on art therapy with adult BMT patients is very limit. Gabriel, Bromberg, Vandenvoerkamp, Walka, Kornbligh and Luzzatto (2001) state, “The clinical efficacy of art therapy remains largely unevaluated, and there is no literature so far about the use of art therapy interventions with adult cancer patients in isolation for BMT” (pg. 114). Gunter (2000) published a study of art therapy with children going through the BMT process. He concluded that art therapy could be used as a way to stabilize defenses of children. Art therapy with adult BMT patients is a relatively new subject.

In order to see if art therapy would be a feasible intervention for adult BMT patients in isolation, Gabriel, et al. (2001) using *The Creative Journey* as the art task. *The Creative Journey* is a structured manual that included ten different art projects. Patients were also given an art kit that contained a variety of art materials.

The results of the study indicated that art therapy is an effective intervention. It claimed “adult BMT patients in isolation may use art therapy to fulfill a variety of emotional needs: (a) to strengthen positive thoughts, (b) to resolve distressing emotional conflicts, (c) to deepen the awareness of existential and spiritual issues, and (d) to facilitate communication with relatives and friends...Both groups were able to make use of the metaphoric quality of art therapy, in a safe and confidential setting.” (pg. 122).

Greece (2003) agreed with Gabriel, et al. (2001). She used art therapy as an intervention with a Vietnam veteran while he was in isolation. The case study found that

art therapy benefited the patient in many ways such as, “increased support system as well as an opportunity for self-expression and self-examination” (Greece, 2003, pg. 236). The art therapy process helped increase communication with team members. Information that was shared during art therapy provided to the staff to better understand the patient.

Adult BMT patients in isolation have had few chances to describe their experience non-verbally and verbally. By creating artwork, the adult BMT patients may have the opportunity to understand their experience of being BMT patients in isolation.

## CHAPTER 3: METHODOLOGY

### *Design of the Study*

In order to understand the lived experience of an adult blood and marrow transplant (BMT) patient in isolation, the research method used was a phenomenological method. Instead of focusing on a few psychological and psychosocial features that may occur while in isolation, “phenomenology is concerned with wholeness, with examining entities from many sides, angles, and perspectives until a unified vision of the essences of a phenomenon or experience is achieved” (Moustakas, 1994, pg. 58).

The purpose of this qualitative research (using art productions of subjects as phenomenological data) study was to explore the lived experience of adult BMT patients in isolation via art productions which emerge from a specific directive and an in-depth interview. It is necessary to research their experience because many psychiatric and psychosocial effects may occur while in isolation and this study will add to the body of knowledge. While there is an increasing amount of literature being done on such effects, “much of this literature is nonempirical and consists of clinical observations, discussions of case histories, and suggestions of strategies for clinical management and intervention in the BMT (bone marrow transplant) setting” (Andrykowski, 1994, pg. 14).

There is an increasing amount of research offered that is focused on the conscious (cognitive) experience of adult BMT patients in isolation. However, there is limited amount of research offered that provides the conscious (verbal) and unconscious (non-verbal). In fact, only two studies were found which suggest the value of art therapy on adult bone marrow recipients.

The study involved two parts: an art-making task and an in-depth interview to allow the adult blood and marrow transplant patients in isolation an opportunity to express their lived experience non-verbally and verbally.

#### *Location of the Study*

The study was located at a large University Hospital, in Philadelphia, PA. The researcher met with the BMT patient in the isolation unit.

#### *Time Period for Study*

The study took place after it was approved by hospital's Internal Review Board (IRB) and Drexel's IRB to November 1, 2008.

#### *Enrollment Information*

The two participants in this study were patients that received a blood and marrow transplant. They were in isolation at the time of the study.

#### *Subject Type*

The subjects that were recruited for the study were adult blood and marrow transplant patients within the ages of 18-years-old and 70-years-old.

#### *Subject Source*

Subjects were patients in isolation on the Blood and Marrow Transplant Unit in a large University Hospital.

#### *Recruitment*

The researcher met with medical staff on the BMT unit. The researcher presented the study and trained the staff about the requirements for the study. Medical staff were given flyers (see Appendix 1) with inclusion and exclusion criteria for participation in the study. Medical staff met with patients individually, whom they felt would fit the criteria

of the study. The patients were given the flyer. If interested, the patient asked medical staff to contact the researcher, or contacted the research directly. The researcher asked if the prospective subject met the criteria. The researcher then met with each participant individually to explain the study more in depth, answer any questions the patient had, and to go over the consent form if the patient had agreed to participate.

The participants were given a \$25 gift certificate. In order to receive the gift certificate, patients had to complete all parts of the study: informed consent, art making directive and open-ended interview.

#### *Subject Inclusion Criteria*

- Subject was an adult BMT patient in isolation at the large University Hospital.
- Subject was able and willing to participate in art-making directive and in-depth interview.
- Subject had to be in isolation for at least 10 days to be able to address the relevant theme.

#### *Subject Exclusion Criteria*

- Subject had a history of inpatient hospitalization for a psychiatric disorder or drug and alcohol abuse prior to BMT.
- Subject was not under 18 years old or over 70.
- Subject was not in isolation for less than 10 days.

#### *Investigational Methods and Procedures*

Two adult BMT patients in isolation participated in this qualitative study, involving an art making task and an in depth open-ended interview. The study took place in the BMT unit at a large University Hospital, located in Philadelphia, PA. The patients

were informed of the study by the medical staff and given a flyer with the inclusion and exclusion criteria. The patient notified medical staff or the researcher directly in order to self-select their self for the study. The researcher was approved by the IRB to accept up to four participants for the study. Two subjects fit the study criteria and volunteered to participate in the study.

This study took place on the BMT unit. The researcher offered both participants the option of doing the study in their private rooms. However, both participants requested to complete in the study outside of their hospital room. One study took place in the hallway of the unit; the other took place in the family kitchen (a kitchen offered to the patients on the unit).

Each meeting lasted between 45 minutes to 90 minutes. It consisted of the following: informed consent and data collection. Both participants met with the researcher in two separate meetings. During the first meeting, the researcher and the participant went through the consent form. The researcher answered any questions the participants had. During the second meeting, the researcher collected data from the participants.

The data collection took place in two parts: an art-making process and an in-depth interview. The participants were told the directions of both parts before data collection began. During the art-making process, each patient was offered the same art materials. A variety of art materials (i.e. markers, pencils and craypas) and two different sized pieces of drawing paper (9" x 12" and 12" x 18") were given to each participant to draw their lived experience of being an adult BMT patient in isolation. The researcher asked the patient to create artwork about being in isolation for this phase of their treatment for

their disease. The patients remained silent during the art making process, while the researcher observed them drawing. When the participant told the researcher their picture was complete, the researcher started the second part of the data collection, the in depth verbal interview.

During the interview process, the researcher did not process the artwork with the participants. The researcher had prepared questions to ask the participants. When the participants referenced their artwork, the researcher responded as minimally as possibly. The reason for minimal response is so that the participant's responses to their artwork and experience would not be influenced by the researcher's comments. The purpose of this study was to obtain information rather than to provide a therapy session. The interview was transcribed in order to look for common themes between the two patients and then the tape was destroyed for confidential purposes.

#### *Informed Consent (10-15 minutes)*

The researcher met with each patient individually to go over consent forms for the study. The patients were informed that the interview was tape-recorded and transcribed. For confidentiality purposes, the tape-recording was destroyed and the names of the patients' friends and family were changed by the researcher in the transcriptions. Also, the researcher made sure to conceal the patient's name in the art product to ensure confidentiality.

The researcher made it clear that the patient may withdraw from the study at any time with no consequence to their medical treatment. Once the researcher had gone over all consent forms, the researcher asked the patient to repeat in their own words their understanding of their participation in the study. The patient was asked to sign the



consent forms. There were three copies of the consent forms. One copy was given to the participant, one copy was given to the principal investigator of the study, and the other was locked and stored in the Hahnemann Creative Arts in Therapy offices.

### *Data Collection*

#### *Introduction (5 minutes)*

Moustakas (1994) states, “The interviewer is responsible for creating a climate in which the research participant will feel comfortable and will respond honestly and comprehensively” (pg. 114). Before the art-making directive, the researcher began with a short conversation with the participant discussing the interest of the study.

#### *Art-making Directive (20-30 minutes)*

The researcher explained the art-making directive as follows: *What is it like to have your illness and be in isolation? Using the art materials, create art that describes your experience.*

Each participant was told that there was no right or wrong way to make art and to try their best. The participant had the opportunity to describe their lived experience, as she depicted in the artwork, verbally during the interview.

#### *Open-Ended Phenomenological Interview (30-40 minutes)*

Moustakas (1994) describes a phenomenological interview as follows:

The phenomenological interview involves an informal, interactive process and utilizes open-ended comments and questions. Although the primary researcher may in advance develop a series of questions aimed at evoking a comprehensive account of the person’s experience of the phenomenon, these are varied, altered,

or not used at all when the co-researcher shares the full story of his or her experience of the bracketed question (pg. 114).

The researcher prepared the following questions to ask the adult BMT patient in isolation are as follows:

- What is the lived experience of an adult BMT patient in isolation?
- How did you depict your experience in your artwork associations with the art materials?
- Do you feel that any issues, conflicts, feelings or thoughts came out verbally during the interview that has not come up before because of the art-making process? If so, what?

#### *Closure Procedure*

Once the researcher finished interviewing the patient, the researcher thanked the patient for their time. There was five minutes of closure to summarize the material that were discussed between researcher and patient. If necessary, medical staff and mental health staff were onsite during the interview.

#### *Data Analysis*

According to Moustakas (1994), “Through phenomenology a significant methodology is developed for investigating human experience and for deriving knowledge from a state of pure consciousness” (pg. 101). Data analysis consisted of four components: the epoche process, phenomenological reduction, imaginative variation, and synthesis of meanings and essences.

The first component, epoche process the researcher puts asides their “prejudgements, biases, and preconceived ideas about things” (Moustakas, 1994, pg. 85).

The epoche process is crucial in phenomenology because it “is the first step in coming to know things, in being inclined toward seeing things as they appear, in returning to things themselves, free of prejudgments and preconceptions” (Moustakas, 1994, pg. 90). With a mindset free of prejudgments and preconceptions, the researcher was able to understand the full essence of the phenomenon.

The second component is called phenomenological reduction. During this process, “the task is that of describing in textural language just what one sees, not only in terms of the external object but also the internal act of consciousness, the experience as such, the rhythm and relationship between phenomenon and self” (Moustakas, 1994, pg. 90). During phenomenological reduction, the researcher viewed the phenomenon from many different perceptions. There are multiple steps that take place during phenomenological reduction. Moustakas (1994) summarizes the steps as follows:

*Bracketing*, in which the focus of the research is placed in brackets, everything else is set aside so that the entire research process is rooted solely on topic and question; *horizontalizing*, every statement initially is treated as having equal value. Later, statements irrelevant to the topic and question as well as those that are repetitive or overlapping are deleted, leaving only the *Horizons* (the textural meanings and invariant constituents of the phenomenon); *Clustering the Horizons Into Themes*; and *Organizing the Horizons and Themes Into a Coherent Textural Description* of the phenomenon.

After phenomenological reduction, the next step of data analysis is called imaginative variation. Moustakas (1994) states, “The task of Imaginative Variation is to seek possible meanings through the utilization of imagination, varying the frames of

reference, employing polarities and reversals, and approaching the phenomenon from divergent perspectives, different positions, roles, or functions” (pp. 97-98). “Imaginative Variation enables the researcher to derive structural themes from textural descriptions that have been obtained through Phenomenological Reduction” (Moustakas, 1994, pg. 99). This process allowed the researcher opportunity to explore the multiple meanings of the phenomenon in order to fully understand the essence of the phenomenon.

The final step in data analysis is called synthesis of meanings and essences. During this process, the researcher incorporates “the fundamental textural and structural descriptions into a unified statement of the essences of the experience of the phenomenon as a whole” (Moustakas, 1994, pg. 100). During the final step, the researcher was able to understand the phenomenon as it is and describe the experience as a whole.

#### *Possible Risks and Discomforts to Subjects*

This study may cause a patient to feel upset or discomfort due to describing their lived experience as an adult BMT patient in isolation. Even though this study involved minimal risk, the art-making and interview may result in underlying issues the patient had to emerge. Unconscious issues and/or emotions may become conscious and expressed.

#### *Special Precautions to Minimize Risk or Hazards*

If the patient becomes physically ill during the art-making process and/or interview (e.g. nausea, headache), medical staff was onsite to aid the patient. Also, mental health staff were onsite to provide further support if necessary after the study. There was five minutes of closure to summarize the material that was discussed between researcher and patient.

## CHAPTER 4: RESULTS

The lived experience of being an adult blood and marrow patient in isolation goes beyond being physically ill in isolation. A transplant physically and mentally transforms each patient differently. It may invade their body and mind. In doing so, the transplant forces the patient to regress. The protective environment becomes one's home, life, and womb. A new person may be reborn or often is involved in a transformation. The patient often becomes dependent on staff and others, just like a baby is to his or her mother. Leaving the isolative environment is not an option for the patient and can be a dream and a nightmare at the same time. There is no telling when discharge will come, or if that time will come. All the patient can do is wait with their body.

### *Overview*

In order to understand what the experience of an adult blood and marrow transplant patient in isolation, the data is presented in the following order. First, a description of both participants was provided. Next, the analysis of data was described. Initially, the researcher needed to develop themes through phenomenological methods. Next, each participant's relevant themes and verbal statements were placed into separate tables. Further investigation was used to composite both participant's experiences into revised themes. Next, the data was analyzed further. Based on the collected data, the researcher was able to integrate the composite textural and structural descriptions in order to discover the true essence and meaning of the isolation experience while on the blood and marrow transplant unit.

### *Participants*

Two adult Blood and Marrow Transplant (BMT) patients from a large University Hospital took part in my study. Both participants met the exclusion and inclusion criteria to participate. The first participant signed her consent form during the first meeting with the researcher, and confirmed the data collection portion. The second participant signed the consent form and met with the researcher in a single meeting.

The first participant, was a 43-year-old African American female diagnosed with acute myelogenous leukemia (AML). She had received a haploid allogeneic transplant from her sister on October 25, 2007. After approximately two months, she was discharged from the hospital. Then, she was readmitted shortly after, on December 27, 2007 with blood clots in her urine. She has been on the BMT isolation unit since then. She was interviewed in the beginning of March, approximately 2 months since she was admitted on the unit.

The second participant, was a 50-year-old Caucasian female diagnosed with Hodgkin's Lymphoma in November 2006. She was admitted to the BMT unit approximately a week before she received her autologous transplant (on February 15, 2008). She has been on the BMT isolation unit since then. She was also interviewed in the beginning of March, approximately one month since she had been admitted on the unit.

For confidentiality purposes, the first subject will be referred to as "Kate" and the second subject will be referred to as "Connie."

#### *Analysis of the Data*

The researcher went through the epoche process prior to analyzing data (see literature review for explanation). The researcher was able to collect and analyze the data

from the two Participants. Through Phenomenological Reduction, certain themes from each Participant's verbal interview were analyzed.

The first participant's themes were as follows:

1. Time
2. Physical illness
3. Home
4. Disease
5. Not knowing
6. Art materials
7. Describing artwork
8. Art making experience
9. Comparing
10. Staff
11. Never being sick
12. Being a "big girl"
13. Hope

The second participant's themes were as follows:

1. Time
2. Disease
3. Physical illness
4. Mental debilitation
5. Religion/Faith/Spirituality
6. Family

7. Comparing
8. Staff
9. Not knowing
10. Describing artwork
11. Transplant procedure
12. Her mother
13. Home
14. Art making experience
15. Hope

The themes both subjects had in common were as follows:

1. Time
2. Physical illness
3. Home
4. Disease
5. Not knowing
6. Describing artwork
7. Art making experience
8. Comparing
9. Staff
10. Hope

The themes described above have been developed from verbatim transcriptions of the subjects while in isolation. The following tables present the themes that developed through the verbal statements made by each participant.



## Participant 1

Table 1:

Themes that developed from verbal statements about the experience of being a blood and marrow transplant (BMT) patient in isolation from a 43-year-old African American female diagnosed with acute myelogenous leukemia (AML).

Themes	Verbal Statements
Time	<ul style="list-style-type: none"> <li>But, when you come in here, they tell you, you gonna be in here for six to eight weeks...and you trust you. You trust you that you are going to be in here for six to eight weeks...</li> </ul>
Physical illness	<ul style="list-style-type: none"> <li>Yeah...sometimes you get sick and throw up. Sometimes...sometimes you have a bad reaction to something...</li> </ul>
Home	<ul style="list-style-type: none"> <li>... they're not letting you go home unless you feel good. If you feel good, they let you go home. If you don't feel good, you're stay'n right here.</li> <li>... 'cause they know you away from home and you want to go home...But...you can't 'cause you're sick.</li> <li>It's like, you want to go home and you can't go home...and there ain't nothing you can do about it.</li> </ul>

Disease	<ul style="list-style-type: none"> <li>• Umm... So...so...it's not easy, it's hard...everybody may think it might be easy, but it's not...especially when you're getting somebody else's cells in your body.</li> <li>• ...It's been like a rocky road...</li> <li>• It's like a battle...</li> <li>• ...'Cause you don't know if your body is going to accept it or not. And um...</li> <li>• Your cells are trying to accept somebody else's cells when you're not 100%.</li> </ul>
Not knowing	<ul style="list-style-type: none"> <li>• I don't know what 100% is like because I've never had 100%.</li> <li>• And...you start spaz'n out and you don't know what to do...</li> </ul>
Art materials	<ul style="list-style-type: none"> <li>• ...you can't use real real real real real light colors because then you won't be able to see what the picture is..what the picture is saying.</li> <li>• ...So you got to use some dark colors.</li> </ul>
Describing artwork	<ul style="list-style-type: none"> <li>• Yeah...you got a desk....you got a bed...chair...you got the window...you got the stuff hanging from the wall...</li> <li>• ...You got the uhh...nurse call button...your tv button...</li> </ul>

	<ul style="list-style-type: none"> <li>• Uh hmm...you got the bed...you got the wheels under the bed...</li> <li>• Closet door...</li> <li>• That's one of them bags hanging off of the wall.</li> </ul>
Art making experience	<ul style="list-style-type: none"> <li>• Well...this artwork couldn't explain any experience...I don't know how many pictures it would to explain the experience... 'cause sometime... you can't...sometimes you can't draw experience...sometimes you gotta just tell it...</li> <li>• I couldn't draw everything that happened in there.</li> </ul>
Comparing	<ul style="list-style-type: none"> <li>• For somebody, else it might just be like...they want them to hurry up and get it under control...</li> <li>• I mean we have fun times too. They try to make it...well..for me...I don't know about nobody else...they try to make it...you know...as uhh...pleasant as possible...</li> </ul>
Staff	<ul style="list-style-type: none"> <li>• ...and all of the nurses come running in and...</li> </ul>
Never being sick	<ul style="list-style-type: none"> <li>• Well..for me...for me it's scary because I've never been sick before.</li> </ul>

	<ul style="list-style-type: none"> <li>• ...they ask me a lot of questions because like I said, I've never been sick before. They ask me a million questions.</li> <li>• New... Yeah. 'Cause like I've been saying, I have never been sick before in my life. So, the experience has been new.</li> </ul>
Being a "big girl"	<ul style="list-style-type: none"> <li>• You have to be a big girl.</li> </ul>
Hope	<ul style="list-style-type: none"> <li>• It can mean, bare with it. It can't be that bad. I mean you're still here, you're still breath'n...you got people to talk to.</li> </ul>

Figure 1:

Participant 1's Artwork



Table 2  
Themes and Artistic Characteristics Developed During Art-Making Task by Participant 1

Themes	Artistic Characteristics
Isolation/Loneliness	<ul style="list-style-type: none"> <li>• No figures</li> <li>• There are distinct separations between objects</li> </ul>
Anxiety	<ul style="list-style-type: none"> <li>• Shaky line quality</li> </ul>
Confinement	<ul style="list-style-type: none"> <li>• Repeated lines in a confined space</li> <li>• The lines on the pictures appear to look like prison bars</li> <li>• The red color appears to be highly confined within the bed</li> <li>• Reference to outside/inside</li> </ul>
Depression	<ul style="list-style-type: none"> <li>• Limited use of color</li> <li>• Significant use of color gray</li> </ul>
Need for Control	<ul style="list-style-type: none"> <li>• Grid-like images</li> <li>• Used structured art materials</li> </ul>
Dependence	<ul style="list-style-type: none"> <li>• The orange lines coming out from the bed appear to look like arms reaching for something</li> <li>• Patient made sure to draw nurse call button</li> <li>• Using the side of the page for the objects to lean up against</li> </ul>
Immobility	<ul style="list-style-type: none"> <li>• The wheels on the bed look like they are turned upward, causing the bed to stay in one place</li> </ul>

	<ul style="list-style-type: none"><li>• The wheels appear to look like restraints</li></ul>
Isolation of Affect	<ul style="list-style-type: none"><li>• Separate colors used to represent each object, especially the use of red in the middle of the paper</li></ul>
Frustration	<ul style="list-style-type: none"><li>• The bed was the central object, that appeared to have a heavy and confined quality</li><li>• The color could symbolize anger or frustrated</li></ul>
Transplant	<ul style="list-style-type: none"><li>• The excessive amount of red used in the picture could represent blood</li><li>• The bed appeared to look like a human reaching up for something</li><li>• The bed could unconsciously represent the patient's body, with cells floating in it</li></ul>

## Participant 2

Table 3:

Themes that developed from verbal statements about the experience of being a blood and marrow transplant (BMT) patient in isolation from a 50-year-old Caucasian female diagnosed with Hodgkin's Lymphoma.

Themes	Verbal Statements
Time	<ul style="list-style-type: none"> <li>• Today, which is only...in isolation...which has...it's not been a month yet...it's been uhh..it's...in the beginning it was...you know...uhh.. it was exciting going into the transplant.</li> <li>• If you gave me a week and...</li> </ul>
Disease	<ul style="list-style-type: none"> <li>• But...uhh..getting the new cells, means you have a new birthday.</li> </ul>
Physical illness	<ul style="list-style-type: none"> <li>• ... So...and everything was good to me until... after...I mean...I'm talk'n physically, not.....not surroundings wise here...Um..about..until like three days ago til now..four days ago...since the last time I talked to you.</li> <li>• And I..I..It took over my body...with diarrhea</li> </ul>



	and...and uh...nausea...and I couldn't even get out of bed one day...
Mental debilitation	<ul style="list-style-type: none"> <li>• It's debilitating...mentally...debilitating.</li> </ul>
Religion/Faith/Spirituality	<ul style="list-style-type: none"> <li>• I believe the Lord is going to heal me with this...I'm a religious person...</li> </ul>
Family	<ul style="list-style-type: none"> <li>• ...and I believe in my family</li> </ul>
Comparing	<ul style="list-style-type: none"> <li>• ...I just get down...Just like everybody else gets down.</li> <li>• So it's...it's uh...I...when you look at statistics, the statistics tell you to go to bigger hospitals. Ann Arbor Institute...umm...Sloan Ketterington... MP Anderson is a big one...that a lot of people go to.</li> </ul>
Staff	<ul style="list-style-type: none"> <li>• But the...the unit here...has been excellent...</li> <li>• Like...it's cause of staff... They're wonderful nurses.</li> <li>• I mean really wonderful nurses. Uh...they'll go out of your way. Sarah* went down bought me a pack of lifesavers off of the street yesterday. And...and...that's a lot for them to go off this floor...they don't ....they don't like to go off the floor...but... they have to scrub all over again...they don't... they don't like to</li> </ul>

	<p>go to lunch. They order in all the time, you know...</p> <ul style="list-style-type: none"> <li>• ...and when the nurses...like you know...you know...have 5 minutes to talk to ya, they do. And they made it a lot...a lot nicer.</li> <li>• Great staff...</li> <li>• ...and she's so little. She's like 80 pounds....And she could...I was watching her. She was so intense. And I...and she...her hand was turning purple.</li> <li>• And uh, she was...she was gone and we were having trouble with my port the day before...the day before that...and...and uh she really did all she could to get that going.</li> </ul>
Not knowing	<ul style="list-style-type: none"> <li>• I didn't expect and...to be honest with you, I thought I made a wrong decision coming to [the hospital].....for the kind of Hodgkin's I have...'cause they don't...uhh they don't really...they don't have...they didn't have a history of doing a lot of Hodgkin's Lymphoma.</li> <li>• Yeah, I mean they do transplants...but they don't...people on the floor don't have</li> </ul>

	Hodgkin's lymphoma...and the kind of Hodgkin's I have.
Describing artwork	<ul style="list-style-type: none"> <li>• Basically...I just wrote different comments on a chart.</li> <li>• Just different comments I made about the...you know you have happy days. Things you think about. You know...I think about work...you know, what's going on there...while I'm here.</li> </ul>
Transplant procedure	<ul style="list-style-type: none"> <li>• ...it was my only option...</li> <li>• But I just made up my mind...and just...the best thing for me. And the minute I got here... I sensed it was the right place.</li> <li>• Kelly*...the day of the transplant, she pushed these big needles in my arm.</li> <li>• You have to do it at a certain time sequence. Once they're unfrozen, they have to...I think like... there is like 8 minutes they have to be uh...out.</li> </ul>
Her mother	<ul style="list-style-type: none"> <li>• Because um...we're very close...</li> <li>• I'm not married. I live with my 81-year-old mom.</li> </ul>

	<ul style="list-style-type: none"><li>• I...I don't have to worry about her...for her needs...because my brother is taking care of her with my sister-in-law...and they're just like me...taking care of her. But, she misses me.</li><li>• And she worries about me... her at this time...she's not in great health...that's why I worry.</li><li>• She ..she can't...um...she can't walk without a walker. When you see her...she would...you would think she's just fine. She's a nervous..she has high blood pressure. She had breast cancer... two months after I was diagnosed with this, she was diagnosed with breast cancer.</li><li>• So we had to deal with that, while I was doing this. So like....I got to...we had to divide up shifts.. I had to take care of..you know...of all my appointments...And you know Bob* would take care of uh...of uh.. I mean, Jane*, my sister-in-law, would take care of my mom.</li><li>• And she had to go 6...she had a mysec...mysectomy done...and it was</li></ul>
--	--

	<p>cancerous...so they wanted to do 6 and a half weeks of radiation.</p> <ul style="list-style-type: none"><li>• And they did it. And...and it's gone now. So she's cancer free with that but it takes a lot out of you when you're 80 something like that.</li><li>• She'll be 82. So that's...that's yeah...that bothers me when she's...you know...when she's home alone. My nieces and nephews stay there during the night with her but...you know..she misses me...my company.</li><li>• Yeah. 'Cause I'm worrying about her now.</li><li>• Yeah, 'cause I'm close to her. And we've gotten closer since I've been sicker...sick.</li><li>• Yeah, well when I was at work...normal everyday...back uh... two years ago, she wouldn't see me from you know... six o'clock in the morning til seven at night...it was different.</li><li>• But this is...I...ever since I have been sick and have been home a lot...she's like...grown...and I can see her... and my brother sees it too in her...her health...it has taken a toll on her...you know...the emotional</li></ul>
--	---

	<p>stress...</p> <ul style="list-style-type: none"> <li>• Yeah and he sees how much she can take...her breathing heavy...and...you know...we get nervous for her.</li> </ul>
Home	<ul style="list-style-type: none"> <li>• You know she knew I was going home...and I'd come home...we would watch a couple of television shows...</li> <li>• Yeah....and at the end I wrote who I miss the most.....sleeping in my bed!</li> </ul>
Art making experience	<ul style="list-style-type: none"> <li>• ...Yeah, I think so...it makes you...you know....It just makes you want to write everything it down.</li> <li>• Yeah...I didn't know what to do...I didn't feel like writing flowers and collage and drew a picture and that interpreted them.</li> <li>• ...I'm really not that artistic.</li> </ul>
Hope	<ul style="list-style-type: none"> <li>• ...It will be okay.</li> <li>• You know I don't have doubts...</li> </ul>

Figure 2:

Participant 2's Artwork



Table 4  
Themes and Artistic Characteristics Developed During Art-Making Task by Participant 2

Themes	Artistic Characteristics
Isolation/Loneliness	<ul style="list-style-type: none"> <li>• No figures</li> <li>• There are distinct separations</li> <li>• Wrote, “There is loniness” (It appeared she meant loneliness)</li> </ul>
Anxiety	<ul style="list-style-type: none"> <li>• Shaky line quality</li> </ul>
Confinement	<ul style="list-style-type: none"> <li>• Repeated lines in a confined space</li> <li>• The lines on the pictures appear to look like prison bars</li> <li>• Wrote, “When it’s your 50 birthday – and stuck in isolation”</li> <li>• Referenced the outside world (ex. Work and home)</li> </ul>
Depression	<ul style="list-style-type: none"> <li>• Limited use of color</li> <li>• The color gray took over the writing</li> <li>• Mentioned missing family members</li> </ul>
Need for Control	<ul style="list-style-type: none"> <li>• Grid-like image</li> <li>• Used structured art materials</li> </ul>
Need for Organization	<ul style="list-style-type: none"> <li>• Patient started her artwork by creating a grid and writing in the grid from left to right</li> </ul>



Dependence	<ul style="list-style-type: none"> <li>• Mentioned the staff (“the staff made it feel a lot better”)</li> </ul>
Isolation of Affect	<ul style="list-style-type: none"> <li>• Patient started with a wide range of colors to express her experience, but ended up using the color gray towards the end</li> </ul>
Frustration	<ul style="list-style-type: none"> <li>• “Sleeping in my bed!” was the only statement written down with an exclamation mark and it took up three of the blocks</li> </ul>
Reference to transplant	<ul style="list-style-type: none"> <li>• “Transplant begins”</li> <li>• “...pushing the cells (in) me”</li> <li>• The color pink used to create the chart could be seen as the color of flesh</li> </ul>

### *Textural Description of Participant 1*

Kate was able to describe her experience as an adult blood and marrow transplant patient in isolation verbally (through the in-depth interview) and non-verbally (through the art making process). The participant had been readmitted into the isolation unit with blood clots in her urine. She had already been in isolation previously for a couple of months, discharged, and then readmitted. The first statement she used to describe the experience was, “Well...it’s not fun.” She admitted that the art making process was not enough to describe her experience by stating, “...I don’t know how many pictures it would to explain the experience...” It was evident that her experience had been mentally and physically challenging.

Time was a huge factor in the BMT process for Kate. She related time and trust together when she explained what the doctors tell a BMT patient, “...they tell you, you gonna be in here for six to eight weeks...and you trust you. You trust you that you are going to be in here for six-eight weeks...” It was apparent that if a patient does not feel well, the patient is not leaving the unit and going home.

Going home was another concern that Kate had. Kate explained going home was based on what the doctor thought and how the patient felt. She stated, “...they’re not letting you go home unless you feel good. If you feel good, they let you go home. If you don’t feel good, you’re stay’n right here.” Later in the interview she also stated, “: It’s like, you want to go home and you can’t go home...and there ain’t nothing you can do about it.”

Feelings of not knowing and fear emerged in the interview. Kate described these feelings when she described her illness, “so...it’s not easy, it’s hard...everybody may think it might be easy, but it’s not...especially when you’re getting somebody else’s cells in your body.” Kate described someone else’s cells in her body as a difficult task. In fact, Kate described this difficult aspect as follows, “It’s like a battle. Your cells are trying to accept somebody else’s cells when you’re not 100%.”

The participant made it apparent that she wanted the dark colors to express her artwork. She stated, “...you can’t use real real real real real light colors because then you won’t be able to see what the picture is..what the picture is saying.” When describing her artwork, she described many details of her room, “.....you got a desk....you got a bed...chair...you got the window...you got the stuff hanging from the wall...” However, after describing the details of her room, she claimed, “I couldn’t draw everything that happened in there.”

The participant then explained the physical illness that she has faced in the room, that she did not draw, “...sometimes you get sick and throw up.....sometimes you have a bad reaction to something...” Kate mentioned the staff “running in” when a patient has a reaction as described.

The participant’s experience of being a BMT patient in isolation was described as “new.” She claimed, “...’Cause like I’ve been saying, I have never been sick before in my life. So, the experience has been new.” Kate compared her “new” experience with how another person may react, “For somebody, else it might just be like...they want them to hurry up and get it under control...they ask me a lot of questions because like I said, I’ve never been sick before. They ask me a million questions.” Kate also compared her

experience with the staff when she stated, “I mean we have fun times too. They try to make it...well..for me...I don’t know about nobody else...they try to make it...you know...as uhh...pleasant as possible...”

Even though Kate has had an experience that she could not fully describe in her artwork, she did state that she had to be “a big girl.” She stated that being a big girl meant, “It can mean, bare with it. It can’t be that bad. I mean you’re still here, you’re still breath’n...you got people to talk to.” She ended being more hopeful at the end of the session.

### *Textural Description of Participant 2*

Connie had been diagnosed with Hodgkin’s Lymphoma in November 2006. She described the transplant as the last resort when she stated, “.. it was my only option...” When she was asked about her experience, she responded with how much time she had been in isolation, “...it’s not been a month yet...”

When the participant described her experience, she spoke about how the beginning was different than currently. She physically and mentally felt different. She stated, “...getting the new cells, means you have a new birthday. “ The experience “...was exciting going into the transplant.” However, after a few days, Connie’s health started to decompensate.

She described her physical health, “It took over my body...with diarrhea and..and uh...nausea...and I couldn’t even get out of bed one day...” Describing her physical health led a more hopeful conversation. She started to explain how she was going to get through the difficult experience. Connie became tearful during the interview. It was apparent that talking about the experience might have been difficult. She stated, “... I get

through every day because there are two things I... I believe. I believe the Lord is going to heal me with this...I'm a religious person... and I believe in my family."

The participant compared herself to other people in order to explain who she is. She stated, "You know I don't have doubts...I just get down...Just like everybody else gets down." She claimed she has "good days, bad days" like everybody else. Later she explained that she was not if the hospital she was being treated could help her because "they didn't have a history of doing a lot of Hodgkin's Lymphoma...."

When she described her feelings about the unit she was on, she compared herself to the other patients on the floor. It seemed clear that she felt different than the other patients when she stated, "...people on the floor don't have Hodgkin's lymphoma...and the kind of Hodgkin's I have."

The participant noted how excellent the staff was. She stated, "They're wonderful nurses." She described her experience of a nurse going out of her way to get her a pack of lifesavers, "And...and...that's a lot for them to go off this floor...they don't ....they don't like to go off the floor..." She also stated that when the nurses, "...have 5 minutes to talk to ya, they do. And they made it a lot...a lot nicer."

When she described her artwork, she stated, "I just wrote different comments on a chart." The artwork was used as a chart to describe her experience. Once again, she noted how appreciative she was of the staff during the BMT process. Time was also another issue she brought up again when she stated, "You have to do it at a certain time sequence. Once they're unfrozen, they have to...I think like... there is like 8 minutes they have to be uh...out."

The participant's experience was also described as "mentally debilitating." She wrote down comments that described, "Things you think about. You know...I think about work...you know, what's going on there...while I'm here."

A major concern for the participant as a BMT patient in isolation was her mother. She first described the importance of her mother, "I'm not married. I live with my 81-year-old mom." Connie claimed her mother worries about her. Then she described her mother's poor health, "... two months after I was diagnosed with this, she was diagnosed with breast cancer." Even though she survived breast cancer, she described her mother as follows, "She's a nervous..she has high blood pressure." Not only did she worry about her mother's physical health but Connie believed her own illness is causing emotional stress on her mother when she stated, "...it has taken a toll on her...you know...the emotional stress..." Even though her mother is being taken care after by Connie's brother and sister-in-law, and her nieces and nephews stay the night with her, Connie stated, "she misses me...my company." Thinking about her mother added to her experience on the isolation unit because she explained, "I'm worrying about her now." However, later she was more hopeful when describing her mother, "...we get nervous for her...It will be okay."

When she described her art making experience, it seemed she was able to use the artwork as a way to organize her thoughts. She stated, "It just makes you want to write everything it down." She explained her feelings of not wanting to draw anything. She needed to write things down. The participant stated, "I didn't feel like writing flowers." Connie used the artwork to organize her thoughts and feelings. Writing down the BMT process helped her express her overall experience to the researcher.

*Imaginative Variation for Participant 1*

I am sitting in my bedroom, looking out the window. The sound of the school bus approaches, and then fades away. My peers get on the bus, and go to school. I wonder what they are learning today. I cannot think about it too much. Therefore, I sit and wait.

Nothing changes in my room, except for the sun glare. I can fall asleep, wake up, and know what time of day it is by the position of the sun glare on the walls in my room. My mother comes in and shuts the blinds in my room to protect my eyes.

Sometimes, I don't let her open the blinds. It is almost more painful to see the outside world that I cannot enter. I am a prisoner, but have done nothing wrong.

I sit in my room. My life has not changed for the past several weeks. I do not know what day it is. The TV is on, but the sound is not on. It does not matter. I can't concentrate. I think it's the medicine. It looks like a handful of candy. So many different colors and shapes. But, it's not. The medicine seems to make me more sick.

My doctor said it would not take this long. I have been more sick than well. Why am I not getting better? What is wrong with me? Am I so sick that people need to protect themselves when they look at me? Do they think that I am contagious? None of my friends visit anymore.

My mom is trying to help me through this experience. She talks to me and takes care of me. But, this experience is new. I am not sure how to deal with it. I have to be a big girl. If I'm a big girl, I will be able to get through it. No one can see me get upset. Everything will be okay. I just have to get through today.

### *Revised Themes*

- Emphasis on time
- Feeling out of control
- Importance of having protection
- Loss of autonomy
- Focusing on the positives as a means of coping
- Conveying self-comfort

### *Structural Description of Participant 1*

Based on observations derived from the verbal interview and art making process, Participant 1 appeared to emphasize the amount of time she has been on the Blood and Marrow Transplant Unit (BMTU). She expressed this when she explained to the interviewer what the doctor had told her and what she has experienced. She stated, “When you come in here, they tell you, you gonna be in here for six to eight weeks...” She further explained to the interviewer that she “trusted” the doctors when they said she would be on the unit for six to eight weeks. This could lead Participant 1 to feeling out of control of the situation because she cannot control her illness. Because she cannot maintain her health, she must stay on the BMTU. She stated, “If you don’t feel good, you’re stay’n right here.”

Participant 1 further explained her loss of control when she described her transplant procedure. She expressed anxiety and fear when stating, “Your cells are trying to accept somebody else’s cells when you’re not 100%.” She described her transplant procedure as “a battle” and “a rocky road,” both are not easy tasks. Participant



1 also mentioned that she had never been sick before multiple times during the verbal interview. By never experiencing her illness, her “battle” could have been intensified due to not know what to expect.

When asked to draw her experience, Participant 1 appeared to know what to draw almost immediately. She drew a picture of her room. Her room could be viewed as a source of protection. When describing it, she made sure to draw her nurse call button. This act may show that she has become aware that she has become more dependent on the medical staff and on the severity of her disease.

Participant 1 made it known that one picture was not enough to describe her experience as a BMT patient in isolation. When describing her picture, it appeared that many daunting experiences had occurred in her room. She stated, “I couldn’t draw everything that happened in there.”

After the art making process and explaining her experience to the interviewer, Participant 1 unconsciously brought herself to a less vulnerable position. She went from describing the transplant experience as “a battle” to stating, “It can’t be that bad. I mean you’re still here, you’re still breath’n...you got people to talk to.” By reassuring herself things were okay, it appeared that Participant 1 used her own defenses as a way of coping towards the end of the interview.

#### *Imaginative Variation for Participant 2*

Doctor’s orders, take a trip to an island. I have made it to the island. It has been a long trip, but I have finally arrived. The first few days have not been bad. I have a nice bedroom. The view is great! The service is incredible. Whatever I need, the staff accommodates me. However, the island is starting to affect me mentally and physically.

Something I ate or drank on the island has caused me to become very nauseous and have terrible diarrhea. My hair has fallen out. My body is swelling. What is happening to me? I'm transforming into someone new.

There is nothing to do on the island. The only thing to do is think. I think about what is happening at work...and at home. How is my mom? I miss her. I know she misses me. My mother must be lonely without me around. I bet she worries about me. Need to get home so she doesn't worry anymore. When am I going to leave?

I was so excited in the beginning...to get away. Now, I feel guilty for being away so long. I am not allowed to leave until the doctor says I can. I can't take this anymore. I want to go home! I want to sleep in my bed. I want to see my family.

God, I need to get better. There is nothing else I can do, except believe in my family and God. The person I have become on this island may not survive off this island...if I get off this island. I am so unsure and anxious. God, please help me.

#### *Revised themes*

- Emphasis on new beginnings
- Focusing on the mental and physical impact of the disease
- Conveying need for spiritual and social support
- Significant feelings of guilt
- Comparing past and present
- Conveying sense of hopefulness

#### *Structural Description of Participant 2*

Based on data collected from Participant 2, it appeared that she viewed the transplant as a new beginning. She stated, "...getting the new cells, means you have a

new birthday” It was as if she was comparing the past and the present throughout the interview. She described how she was prior to transplant, “...it was exciting going into the transplant...” However, the excitement did not last long when she described how the transplant effected her physically, “It took over my body...with diarrhea and...and uh...nausea...and I couldn’t even get out of bed one day.”

The transplant affected Participant 2 physically. Even though it was a new beginning, it appeared that the transformation was scary. She made sure to tell the interviewer she is like everyone else when she stated, “You know I don’t have doubts...I just get down...Just like everybody else gets down.” It was as if she was unconsciously telling the interviewer she is like everyone else on the inside, even though her appearance does not reflect a healthy person.

Participant 2 started to explain how things were before the transplant again. She stated, “Yeah, well when I was at work...normal everyday...back uh... two years ago, she wouldn’t see me from you know... six o’clock in the morning til seven at night...it was different.” To the participant, life before the transplant was “normal.”

It appeared that she felt considerable amount of guilt. She explained to the interviewer that she lives with her 81-year-old mother and she worries about her. She described her guilt as follows, “She’ll be 82. So that’s...that’s yeah...that bothers me when she’s...you know...when she’s home alone.” Being away from her mother seem to cause Participant 2 emotional stress. Also, having to depend on the nursing staff, her brother and sister-in-law appeared to cause feelings of guilt. She explained to the interviewer that the nurses are “wonderful.” She stated that a nurse went off of the floor to get a pack of Lifesavers for her despite the great inconvenience of leaving the unit.

Her brother and sister-in-law help out with her mother while she was away. Throughout the interview, she expressed how worried she was about her mother, even though she is being cared for. Participant 2 stated, "...she misses me...my company." It is evident that she is not used to being away from her mother.

Although Participant 2 became upset during the interview, she was able to think of the multiple supports she does have: Her faith and her family. She claimed, "I get through every day because there are two things I... I believe. I believe the Lord is going to heal me with this...I'm a religious person...and I believe in my family." This statement emphasizes the importance of faith and family to Participant 2.

During the art making process, Participant 2 was able to use the art materials to express her feelings about her experience, even though she claimed she was "not that artistic." She appeared to use the art materials as a way of organizing her thoughts. She claimed the process "... makes you want to write everything it down."

### Composite Analysis of the Two Participants

The data of the two Participants was brought together in a composite analysis to compare the commonalities of the experience of being a blood and marrow transplant patient in isolation. The subjects' relevant themes, verbal statements, and textural descriptions were used to develop a composite textural description. The composite textural description represents the two participants experiences as a whole. Next, revised themes of the experience as a whole were developed. The themes were used to compose the structural description, which portrayed how the researcher experienced what the participants experienced as a whole. The researcher was able to understand the phenomenon of being an adult blood and marrow transplant patient in isolation via these two women's experiences. The researcher also looked at the artwork that was created by the two participants during the data collection process. Common themes in the artwork were found and were used to further explain the lived experience.

Table 5  
Composite Themes Developed From Verbal Interview of the Two Participants

Themes	Verbal Statements
Facing the unknown	<ul style="list-style-type: none"> <li>• But, when you come in here, they tell you, you gonna be in here for six to eight weeks...and you trust you. You trust you that you are going to be in here for six to eight weeks...</li> <li>• ...everybody may think it might be easy, but it's not...especially when you're getting somebody else's cells in your body</li> <li>• ...It's been like a rocky road...</li> <li>• It's like a battle...</li> <li>• ...'Cause you don't know if your body is going to accept it or not</li> <li>• Your cells are trying to accept somebody else's cells when you're not 100%.</li> <li>• I don't know how many pictures it would to explain the experience</li> <li>• I couldn't draw everything that happened in there</li> <li>• ...for me it's scary because I've never been sick before.</li> <li>• They ask me a million questions</li> <li>• So, the experience has been new</li> </ul>

	<ul style="list-style-type: none"> <li>• ...in the beginning it was...you know...uhh.. it was exciting going into the transplant</li> <li>• ...getting the new cells, means you have a new birthday</li> <li>• It's debilitating...mentally...debilitating</li> <li>• ...the statistics tell you to go to bigger hospitals</li> <li>• I thought I made a wrong decision coming to [the hospital].....for the kind of Hodgkin's I have...</li> <li>• ...they didn't have a history of doing a lot of Hodgkin's Lymphoma</li> <li>• ...the day of the transplant, she pushed these big needles in my arm</li> <li>• ... two months after I was diagnosed with this, she was diagnosed with breast cancer.</li> </ul>
Decreased sense of self-control	<ul style="list-style-type: none"> <li>• Yeah...sometimes you get sick and throw up. Sometimes...sometimes you have a bad reaction to something...</li> <li>• ... they're not letting you go home unless you feel good.</li> <li>• But...you can't 'cause you're sick.</li> <li>• It's like, you want to go home and you can't go home...and there ain't nothing you can do about</li> </ul>

	<p>it.</p> <ul style="list-style-type: none"> <li>• ...you start spaz'n out and you don't know what to do...and all of the nurses come running in and...</li> <li>• ...and all of the nurses come running in</li> <li>• ...and everything was good to me until...</li> <li>• It took over my body...with diarrhea and..and uh...nausea...and I couldn't even get out of bed one day...</li> <li>• Yeah, well when I was at work...normal everyday...back uh... two years ago, she wouldn't see me from you know... six o'clock in the morning til seven at night...it was different.</li> </ul>
<p>Feelings of isolation and thinking of the world outside of the transplant</p>	<ul style="list-style-type: none"> <li>• ... 'cause they know you away from home and you want to go home...</li> <li>• ...people on the floor don't have Hodgkin's lymphoma...and the kind of Hodgkin's I have</li> <li>• You know...I think about work...you know, what's going on there...while I'm here</li> <li>• she's not in great health...that's why I worry.</li> <li>• She'll be 82. So that's...that's yeah...that bothers me when she's...you know...when she's home alone. My nieces and nephews stay there during</li> </ul>



	<p>the night with her but...you know..she misses me...my company.</p> <ul style="list-style-type: none"> <li>• ‘Cause I’m worrying about her now.</li> <li>• ...her health...it has taken a toll on her...you know...the emotional stress...</li> <li>• ...we get nervous for her.</li> <li>• You know she knew I was going home...and I’d come home...we would watch a couple of television shows...</li> <li>• Yeah....and at the end I wrote who I miss the most.....sleeping in my bed!</li> </ul>
Coping with transplant	<ul style="list-style-type: none"> <li>• I mean we have fun times too</li> <li>• ...they try to make it...you know...as uhh...pleasant as possible</li> <li>• You have to be a big girl</li> <li>• ...bare with it. It can’t be that bad. I mean you’re still here, you’re still breath’n...you got people to talk to</li> <li>• I believe the Lord is going to heal me with this...I’m a religious person...</li> <li>• You know I don’t have doubts.....I just get down...Just like everybody else gets down.</li> <li>• the unit here...has been excellent...</li> </ul>

	<ul style="list-style-type: none"><li>• They're wonderful nurses.</li><li>• And they made it a lot...a lot nicer</li><li>• ...you know you have happy days</li><li>• ...the best thing for me</li><li>• I sensed it was the right place</li></ul>
--	---

Table 6  
Composite Themes and Artistic Characteristics Developed Through the Artwork of the  
Two Participants

<b>Themes</b>	<b>Artistic Characteristics</b>
Isolation/Loneliness	<ul style="list-style-type: none"> <li>• No figures</li> <li>• There are distinct separations between objects</li> </ul>
Anxiety	<ul style="list-style-type: none"> <li>• Shaky line quality</li> </ul>
Confinement	<ul style="list-style-type: none"> <li>• Repeated lines in a confined space</li> <li>• The lines on the pictures appear to look like prison bars</li> <li>• Both pictures represent inside/outside</li> <li>• Both pictures appear to have images about “being stuck” in isolation</li> </ul>
Depression	<ul style="list-style-type: none"> <li>• Limited use of color</li> <li>• Significant use of color gray</li> </ul>
Need for Control	<ul style="list-style-type: none"> <li>• Grid-like images</li> <li>• Used structured art materials</li> </ul>
Dependence	<ul style="list-style-type: none"> <li>• Both pictures represented images of the nursing staff</li> </ul>
Isolation of Affect	<ul style="list-style-type: none"> <li>• Separate colors used to represent each image</li> </ul>
Frustration	<ul style="list-style-type: none"> <li>• Both pictures appeared to have images that could represent frustration</li> </ul>
Transplant	<ul style="list-style-type: none"> <li>• Both pictures appear to have images of cells and</li> </ul>

	the body
--	----------

*Composite Textural Description*

By using the composite themes, verbal statements and artwork created by both Subjects, a composite textural description developed. By bringing all of the data together, an experience of an adult blood and marrow transplant patient in isolation can be viewed as a whole and not solely by individual experiences.

Both participants of the study claimed that the experience was unfamiliar. Participant 1 described the experience as “new” and “scary.” Participant 2 expressed that the transplant had given her a “new birthday” because she received new cells. Even though the transplant was expressed as “new,” it was evident that it lead to feelings of not being in control.

Both Participants explained the physical effects the transplant had on them. Each Participant talked about a physical transformation from a healthy person to a sick person. Participant 1 stated, “...sometimes you get sick and throw up. Sometimes..sometimes you have a bad reaction to something...” Participant 2 described the physical effects as follows, “It took over my body...with diarrhea and..and uh...nausea...” The transplant appeared to be as highly anxiety-provoking. Participant 1 expressed this anxiety when she stated, “Your cells are trying to accept somebody else’s cells when you’re not 100%.” Participant 2 expressed the invasion of the transplant when she stated, “It took over my body...”

Not only was the transplant invasive and anxiety provoking, but also the physical effects caused the Participants to be stuck in isolation. By describing the physical effects, the underlying meaning was the Participants were stuck in isolation. Participant 1

portrayed being stuck in isolation as follows, "... they're not letting you go home unless you feel good." She expressed the fact that the doctors will not let you leave the isolation unit unless you are at a healthy level. Participant 2 focused on the severity of her physical symptoms. She explained to the researcher, "and I couldn't even get out of bed one day..." due to her physical deterioration. The transplant led the patients to feeling confined in their environment.

Confinement appeared to be difficult for the Participants. The Participants shared feelings of isolation to the researcher. Participant 1 expressed her desire to go home, "... 'cause they know you away from home and you want to go home..." Participant 2 thought about her work and expressed feelings of worry for her mother. She described her feelings as follows, "...that bothers me when she's...you know...when she's home alone. My nieces and nephews stay there during the night with her but...you know..she misses me...my company." It is apparent being in an isolative environment for an unknown amount of time have left the Participants feeling out of control.

Participant 1 expressed feeling out of control when she compared her time on the unit with her trust for the doctors. She stated, But, when you come in here, they tell you, you gonna be in here for six to eight weeks...and you trust you. You trust you that you are going to be in here for six to eight weeks..." Both Participants were unable to leave the hospital because of their illness. Participant 1 further explained the feeling of not have control over her body when she stated, "...you start spaz'n out and you don't know what to do...and all of the nurses come running in." The Participants had lost some of their autonomy because of their illness, and had to depend on staff to provide care.

Both participants expressed how excellent the staff was. Participant 1 described her experience with the staff as follows, "...they try to make it...you know...as uhh...pleasant as possible." Participant 2 described the nurses as follows, "And they made it a lot...a lot nicer." It was evident that the nursing staff helped both participants mentally and physically cope with the illness while in isolation and this was readily acknowledged by the participants.

Both Participants were able to participate with the art making section of the data collection. During the verbal interview, the Participants referred to their artwork to describe their experience. Both Participants' artwork reflects their experience in isolation. Participant 2 wrote down, "Room with a view" as a way to describe the beginning of her experience on the unit before the transplant (her room on the unit had a beautiful view of Philadelphia). Participant 1 drew a picture of her bedroom on the unit.

Both Participants chose not to draw themselves in their pictures. This could have been done because they felt like they lacked the artistic skill. Participant 2 stated, "...I'm really not that artistic." However, not drawing themselves in their pictures could also be seen as an unconscious fantasy. They could have used the artwork as a way to "escape" the isolation by not drawing themselves in their pictures. The experience in isolation appeared to be highly anxiety-provoking for Participant 1. She stated, "I don't know how many pictures it would (take?) to explain the experience" and "I couldn't draw everything that happened in there." It seemed that Participant 1 had many different experiences while in isolation. However, after analyzing the artwork, it was evident that her picture did explain a significant amount of information about her experience.

It appeared that both pictures had many separate parts on the page that were not connected. This could be seen as feeling isolated or separated from other people, the outside world or their bodies. Also, both patients used one color to represent each object or text on the picture.

Participant 2 described her artwork as follows, “I just wrote different comments on a chart.” She appeared to organize her thoughts and experience on the paper by drawing a chart. Participant 1 drew a grid or a chart on her picture (which represented a window). The repetition of lines and chart-like images could be seen as a way to obtain control.

Confinement was a major theme seen in both images. Participant 1 drew a window that looked like prison bars. Participant 2 drew a chart, which could unconsciously be interpreted as prison bars. Both pictures reference the outside world. Participant 1 drew a window to represent the outside world. Participant 2 wrote down, “Room with a view.” Participant 2 also referenced her work, family and home within the artwork. The Participants also drew images of being confined in the isolation setting. Participant 1 drew a bed with wheels that look like they are turned upward, which would cause her to remain immobile. Participant 2 wrote, “When it’s your 50 Birthday – And stuck in isolation.” It seemed that the isolation caused stress to both of the Participants.

The pictures appeared to have some characteristics that could reflect anxiety, depression, and frustration. The shaky line quality of both pictures could represent anxiety about being in isolation, their disease or their transplant. Both pictures have a limited use of color. Even though Participant 2 started off using multiple colors in her artwork, mid-way through, she continued to use the color gray until she finished. The

color gray is used throughout Participant 1's picture. It seemed that both pictures contain some frustration. Participant 1 appeared to use a lot of energy to fill the bed up with the color red. Frustration may also be seen within the words of Participant 2's drawing. It appeared that she was so frustrated, she was unable to contain her wording, "Sleeping in my bed!" in the lower right hand corner of her picture. It appeared that being in the hospital bed may have cause some frustration.

Both participants referenced their dependence on the nurses/staff in their artwork. Participant 1 drew the nurse call button on her bed in her picture. Participant 2 wrote down her experience of a nurse giving her her cells through a needle. She wrote, "(Nurse) used all of her might pushing the cells (in) me." When asked to describe their experience of being an adult blood and marrow transplant patient in isolation, it seemed obvious that the true essence of the experience was not just about the individual, but about the staff as well.

Finally, the images appear to represent the Participants transplants. Participant 1 drew a bed, however it appears to look like a body. The body seemed to have objects (that could represent cells) floating within it. Participant 2 made a few references to her transplant and cells within her writing.

The artwork appeared to provide a lot of visual information. Both images seemed to have many overlapping artistic characteristics.

#### *Composite Imaginative Variation*

It was an ordinary day. Sally, a middle-school teacher, arrived home. She said hi to her mother, who was sitting by the fireplace knitting. "Want to order Chinese



tonight?” Sally asked. Her mother responded, “Sure.” Sally called up the usual Chinese take out and sat down near her mother. She put on the evening news.

All of the sudden, Sally heard glass break against the floor. “Mom, are you okay?” Her mother looked up from her knitting needles and replied, “I’m fine. Are you okay?” Sally looked around the house to see where the noise came from. Sure enough, a few panels from the window in the living room window broke, but from what? Glass was everywhere. There was no sign of a rock or stone, nothing.

Just as Sally was about to pick up the pieces of glass, a strong light blinded her from outside the window. What was happening? Her body started to elevate toward to the light. She was being taken from her home by something or someone. She tried to resist leaving. However, when she resisted, she was cut by the glass and finally gave in to the light.

It felt like she was moving up towards space. She felt nauseous and anxious. “What is happening to me?...Where am I going?” she thought to herself. Before Sally knew it, she saw an end to the tunnel of light. It was a door. The door slid open and shut immediately behind it. Sally was taken to a room with a bed, before she could turn around to say thank you, the door slammed behind her. She looked around the room. There was a table with a light and a portable toilet next to the bed. “This looks like a prison,” Sally thought to herself. She walked over to her window. She could see Earth from her bedroom. She was in space.

All of the sudden, there was a loud knock at the door. “Who is it?” asked Sally. A strange being appeared. Sally gasped at the sight of the odd sight. It looked like a person. It had two eyes, but wore a mask over its nose and mouth. Its hands and feet

looked like they were made of rubber. But it's body looked like it was wrapped with layers of linens. "This is your new home," stated the strange being. "Where am I?" asked Sally. "You are where you need to be. You will be taken care of here," stated the strange being.

Sally was confused. "What do you mean, taken care of? I have never been sick in my life. I don't feel sick now." The strange being stated, "You cannot go back to Earth unless we can take care of you." The strange being turned around and left Sally.

Sally started to cry and pray to God that she would be okay. Then she started to think of her mother. "I didn't mean to leave her. Maybe I did not resist enough when I saw the light. I hope she is okay," she told her self. She felt an overwhelming sense of guilt.

Over the next few weeks, Sally noticed herself become weaker. The strange beings would wake her up at all hours of the night. They would give her medicine the size of walnuts and constantly stab her arm with needles. She was told that she had to take all of the medicines, or else she would not get better.

It was difficult to do things that she didn't have to think about before, even taking a shower was a challenge. Before she knew it, she was wearing a diaper, and depended on the strange beings to come in and change her. It was as if she was regressing back to when she was a baby. Sally knew she could not take care of herself. She definitely knew leaving the isolative environment was not an option. There is no way she would be able to survive in space. So, the only thing left to do was wait...and that is what she did.

After a while, she became fearful of leaving the protective territory. "What if I leave, and I die?" she thought to herself. "What if my body cannot survive in a normal

environment?” she hesitated. The day came when the strange being came to her, and stated, “It is time.” Sally became overwhelmed with anxiety. She was ready to see her mother again, but was nervous about going back to Earth. “We are here if you need us,” stated the strange being. “Take care of yourself, and good luck,” it said. Sally waved good-bye. The doors slid open, and she went towards the light once again.

#### *Revised Themes*

- Transformation of self
- Feelings of invasion
- Anxieties about protective confinement
- Loss of autonomy and acceptance of dependence

#### *Synthesis of Composite Textural and Composite Structural Descriptions*

Being an adult blood and marrow transplant patient in isolation is not just being a sick patient in isolation. The data collected from each Participant had many commonalities. Based on the themes that developed through the commonalities, the researcher was able to go beyond the verbal statements and discover the true essence of what the lived experience is of being an adult blood and marrow transplant patient in isolation.

Both participants appeared to transform. Their physical appearance was changing, and their mental state was being challenged while in confinement. There was no control over the transformation. It had to be done in order to survive. Participant 2 described the transplant as her “only option.” Transformation was inevitable when faced with the transplant procedure. There is no way for the Participants to control the transplant experience.

Participant 1 mentioned control when describing her experience, “For somebody, else it might just be like...they want them to hurry up and get it under control...” Even though she is talking about “somebody else” in this statement, it could be seen as her projecting a need for control. She also stated, “And...you start spaz’n out and you don’t know what to do...” It is evident that the transplant can be seen as an uncontrollable invasion of the body.

Participant 2 also found the procedure bodily invasive. When describing the transplant, she stated, “It took over my body.” All of the sudden, the transplant took hold of her and transformed her. The invasion seemed to be strong, that both Participants had slowly lost their autonomy. Due to the physical symptoms caused by the transplant, the Participants found themselves dependent on the staff.

Participant 2 expressed her gratitude toward the nurses constantly during her interview. When talking about the nurses she portrayed the emotional support she received from the nurses as follows, “...they’ll go out of your way.” Participant 1 mentioned, “all of the nurses come running in” when there was a physical problem. It was clear that the nursing staff affected the Participants’ experience physically and mentally.

The Participants appeared to have anxiety about their confined environment on the blood and marrow transplant unit. It was apparent that both Participants missed being home. However, they both were aware that they needed to be confined until they were healthy enough to leave the unit. Participant 1 explained this as follows, “... they’re not letting you go home unless you feel good.” The doctor’s will not advise a patient to go home without being well enough to leave. The patient may fear an environment that is

not germ-conscious after being in a protective environment for so long and not be close to expert help if their health deteriorated and death threatened.

Both Participants were able to create artwork that reflected their experience as a BMT patient in isolation. Each Participant seemed to portray anxiety by drawing shaky lines. Each drawing has a grid-like image within in it. This image could represent the need for organization or control. There is a sense of confinement within the drawings. Participant 1 drew a picture of her bed. She colored in her bed with a red marker. This could have expressed her anger and frustration with being restricted to her bed at times. It could also unconsciously represent her body and the transplant. It appears that the bed is stuck. The wheels can be seen through the bed. Participant 2 surrounded a lot of her written phrases within squares. The lines can also be seen as prison bars. There is a connection to the outside world in both pictures. Participant 1 chose to draw a window and Participant 2 chose to write down people and things she missed from the outside world (ex. Work).

The data that was analyzed provided valuable information about the participants' experience of having their disease in isolation. It seemed that both participants expressed the experience as a physical and mental challenge. The information gathered may be used to help medical staff, mental health staff, and art therapists understand the experience of this population.

## CHAPTER 5: DISCUSSION

### Overview

A blood and marrow transplant (BMT) is a procedure that is usually considered a patient's last resort in treatment. Today, they are more widely used as a source of treatment for many diseases. In order for a patient to prepare for the transplant, she or he must undergo chemotherapy and/or radiation. This process wipes out their immune system, making the patient susceptible to infection. The patient is required to stay in an isolative environment to decrease their chance of infection. While in isolation, the patient waits for the blood counts to rise and for their cells to engraft. During this period of time, a patient may be affected physically as well as psychologically.

The purpose of this study was to explore the lived experience of an adult bone marrow transplant patient in isolation. This was accomplished verbally (through an in-depth interview) and non-verbally (through an art-making task). It was necessary to study this topic because there is a limited amount of research on adult bone marrow transplant patients in isolation. Furthermore, few studies have been done exploring art therapy and adult bone marrow transplant patients.

In order to understand the lived experience of adult BMT patient in isolation, Moustakas' phenomenological research method was used. Two participants took part in the study. Each participant consented to participate in the study. The study consisted of two parts: an art-making task and in depth verbal interview.

The researcher provided each participant with the same art materials (i.e. markers, pencils and crayons) and white 9" x 12" or 12" x 18" drawing paper. The participants were told there was no right or wrong way to make their art, just to try to the best of their

abilities. The art directive was given as follows: *What is it like to have your illness and be in isolation? Using the art materials, create art that describes your experience.*

After the art-making task, each participant took part in an open-ended interview with the researcher. The researcher prepared the following questions for the open-ended interview:

- What is your lived experience of an adult BMT patient in isolation?
- How did you depict your experience in your artwork plus associations with the art materials?
- Do you feel that any issues, conflicts, feelings or thoughts came out verbally during the interview that has not come up before because of the art-making process? If so, what?

In order to capture the true essence and overall experience of being an adult BMT patient in isolation, the researcher made sure to limit responses after the participants answered each question (e.g. Saying, “Yeah...” or “Okay...”) so that the participants were able to give their own answer and not be affected by the researcher.

The data was collected and analyzed using Moustakas’ phenomenological research method. Common themes were discovered within the verbal transcripts of both participants. Similarly, the artwork of both participants reflected similar themes.

The following chapter will discuss the findings of the study. It will also depict potential clinical applications, where the data would be significant and useful. Also, this chapter will address the limitations of the study and discuss future research possibilities.

### Description of Major Themes from Verbal Interviews

The following themes were common between the two adult BMT patients when they described their lived experience of having their illness in isolation:

- Time
- Physical illness
- Home
- Disease
- Not knowing
- Describing artwork
- Art making experience
- Comparing
- Staff
- Hope

In the literature review, it was stated that an adult BMT patient might experience many physiological, psychological and psychosocial challenges. It was not a surprise when these challenges emerged within the stated themes. The two participants were affected physically and psychologically as BMT patients in isolation. They expressed their physical pain by describing their symptoms and disease. The physical symptoms appeared to affect them psychologically too because they did not know when they would be able to go home or if their transplant was going to be successful.

The literature was consistent with the themes that emerged through the interview when it suggested the importance of the nurses on the unit. Both participants of the study were very grateful for the staff. Because the BMT process can be mentally and



physically deteriorating, the participants had to depend on the staff daily. It was not solely because of their physical support as nurses, it was also their emotional support that helped the Participants cope with their experience.

According to the literature, the caregivers (family and/or friends that care for the BMT patient throughout the process) of BMT patients are also impacted immensely. When a patient undergoes a transplant, there will be role changes at the household. Participant 2 expressed feeling guilty when she talked about her family members taking on her role as a caretaker for her mother.

Both participants experienced a role change from being autonomous to dependent. Even though Participant 1 did not mention any caregivers during her interview, she expressed her gratitude and dependence towards the nursing staff. Participant 2 spoke highly of the nursing staff through out her interview as well.

There was also a connection between the themes and the literature when the participants spoke about being in isolation and home. Both Participants expressed their desire to go home but they were unable to because of their transplant. Feelings of abandonment and loneliness appeared to increase because of the isolation time required for the transplant procedure.

Even though many of the findings were consistent with the literature, this study did challenge a “psychological symptom” that was discussed in a few studies. Both Participants spoke about the physical effects of the transplant (i.e. nausea). In general, when a person feels nauseated, she or he is not likely to eat. Andrykowski (1994) and Campbell (1999) claimed that a BMT patient may present different symptoms, one of which is anorexia. According to the DSM-IV (2000), anorexia is defined as “a refusal to

maintain a minimally normal body weight” (pg. 583). It is characterized as more of a choice in the DSM-IV. The participants spoke about their physical illness and transplant process. It appeared that the patients were too nauseated to eat.

The literature also claimed that isolation was enjoyable to some patients (Campbell, 1999). In other words, patients did not mind being alone. On contrast, it seemed that both Participants had anxieties about the protective isolation setting. Participant 1 explained if she was not well enough, she would not be able to leave. Participant 2 appeared to have significant anxiety when explaining how difficult it was to be away from her mother.

Even though there were minor differences, the literature appeared to be consistent with the findings in this study. Composite themes emerged after the Participants’ data were analyzed further. These themes go beyond the prior themes. The revised themes were as follows:

- Transformation of self
- Feelings of invasion
- Anxieties about protective confinement
- Loss of autonomy and acceptance of dependence

With further exploration, the creation of meanings and essences of the experience was uncovered. These findings may help mental health professions, medical staff and other art therapists understand what the lived experience is like for this population.

### Description of the Artwork and Art Making Process

The Participants were able to create images of what it is like being an adult Blood and Marrow Transplant (BMT) patient in isolation. Creating artwork gave the Participants an opportunity to communicate their experiences non-verbally. It also allowed them to use the artwork during the open-ended interview process as a reference.

When asked to draw her experience, Participant 1 drew her room. She spent the most time on the central object (the bed) and the window. She had been suffering from blood clots, and stayed in bed for the majority of the day. It seemed that she represented her frustration, anger and anxiety within the bed when she used the color red to fill the entire space. The bed could represent many things to Participant 1. Visually, the bed appeared to look like a body with arms reaching out. There appeared to be things (perhaps cells) floating within the red body.

Immobility was seen in Participant 1's artwork. The wheels of her bed appear to be over her bed, not under. If the wheel were facing upward, the bed would be immobile. The wheels appear to look like restraints. She could have unconsciously drawn this image to represent her feelings of restriction and immobility.

Red could also symbolize "stop." Participant 1 could feel like she is stuck, or "at a stop sign." There appears to be an object hanging above her bed that has a little color green within in it. When thinking about a stoplight, the amount of red compared to the amount of green in her picture is overwhelming.

When drawing the window, Participant 1 repeatedly drew the lines that represented the blinds. Drawing the lines over and over could have given a sense of

control and mastery to Participant 1. Also, because the window is a large object within her picture, it may unconsciously represent her desire to leave or escape the hospital.

It seemed that she started describing her experience, by describing her room. However, after listing everything in her room, she appeared to go into a deeper level with the researcher. She described her art making process as follows:

...this artwork couldn't explain any experience...I don't know how many pictures it would (take) to explain the experience...'cause sometimes you gotta just tell it...

This statement was very interesting. Art therapists claim the opposite of what Participant 1 stated. The art component can bring out conscious and unconscious imagery, which sometimes patients do not have the words for. However, Participant 1 claimed that one picture was not enough to express her experience and sometimes "you gotta tell it." Even though she made this statement, the artwork appeared to help Participant 1 explain the intensity of her experience.

Participants 2 appeared to use the art-making task as a way to organize and control her experience. She started by drawing horizontal and vertical lines with a pink craypas (the color pink could represent flesh or her body). She claimed that when she thought of her experience, she thought of the chart that hangs in her room. (There is a chart in every patient's room on the floor where nurses write down their daily blood counts.) Starting with the upper left-hand corner, Participant 2 started organizing her thoughts by writing them out on paper. This process could have given Participant 2 may have more control and structure.

In the beginning of her writing, Participant 2 was constantly changing marker colors. However, midway through the “calendar,” she chose the color gray when she wrote, “...on the bad days the staff made it feel a lot better...” She continued to use the color gray until the end of her chart. While writing, she mentioned her family members and hope to be home. The action of going from a variety of colors to gray reflected findings from Holland, et al. (1977) which stated that a patient psychological status in isolation was affected when the physical illness deteriorated. It seemed in the beginning, Participant 2 used a variety of colors to express her experience. However, as the days went by, she chose to write solely with the color gray. Gray may be seen as a dull, depressed color, which could reflect her emotional and physical deteriorations.

It is interesting to note that both Participants did not draw themselves in their artwork. It may have been due to lack of artistic talent. However, the Participants could have been unconsciously displacing them selves outside of isolation.

#### Possible Clinical Applications

This study’s findings could be used as an education tool for blood and marrow patients, caretakers of BMT patients, medical staff, mental health staff, and art therapist. There is limited amount of research done on the experience of adult BMT patient in isolation. There is an even smaller amount of literature that has been done using art as a non-verbal way of communicating their experience with adult BMT patients in isolation. Any information that was uncovered (Gabriel, et al., 2001 and Greece, 2003) could be a valuable tool to any of these populations to help further understand the experience of a BMT patient in isolation. Hopefully with further education, people would become more aware and empathetic to the needs of this specific population.

### Delimitations

There were a few delimitations (imposed by the researcher) to this study. The study consisted of two female participants. The experience of an adult blood and marrow patient in isolation cannot be based on two patients' experiences.

One participant was African American and the other participant was Caucasian. Hoodin, Kalbfleisch, Thornton, and Ratanatharathorn, (2004) described why this might be significant as follows:

...for given medical conditions, the type of BMT patient likely to survive longest was a young, married, educated, European-American, non-smoker who was more defiant, better adjusted, and less depressed. (pg. 150)

The fact that each participant was a different race could have affected the results.

Although, based on the analyzed data from each participant, it is evident that their data did overlap and they had similar experiences.

The findings in this study were based on the experience of adult BMT patients in reverse/protective isolation. The literature claimed that studies based on the experience of different ways of isolation could affect the results. As stated in the literature, there are two ways of isolation: reverse/protective isolation environment (protects patients from getting sick) or source isolation (visitors and staff are protected from getting sick by patient). The study took place on a protective/reverse isolation unit. The patients are able to leave their rooms with a mask on, but cannot leave the isolation unit unless necessary. The experience by each participant could have differed dramatically if source isolation was necessary.

### Limitations

There are a couple of limitations in the study (researcher could not control). For example, both participants knew the researcher. Because BMTU has a small patient population and the stay is long-term, the researcher is able to meet all of the patients on the unit. The participants' answers could have been influenced positively or negatively during the data collection.

Another limitation took place during the interview process. Due to risk of infection, both participants were required to wear masks. The researcher her could have misunderstood a participant's response when transcribing the interview. For example, Participant 2 stated, "I didn't feel like writing flowers and collage..." Wearing masks also limited non-verbal expression.

Even though there were some limitations and delimitations in the study, the findings of the study were important. Both participants were able to describe their illness and how it has affected them in isolation.

### Future Research

The purpose of this study was to understand the lived experience of an adult blood and marrow transplant (BMT) patient in isolation. Participants were able to communicate their experiences verbally (through an open-ended interview) and non-verbally (through an art-making directive). By using the phenomenological method, the researcher was able to synthesize the true essences and meanings of what the experience was for these patients. Further research would be highly significant in order to further understand this population. The following are suggestions for further research:

- Male and female participants

It would be interesting to compare and contrast the experiences of the opposite sexes.

- Recruiting married and non-married participants

The experience of a married BMT participant may be different than a non-married participant. A spouse may provide extra support or stress.

- Recruiting participants with children and without children

It would be interesting to compare and contrast the experiences of participants that have children to those who do not.



## **CHAPTER 6: SUMMARY AND CONCLUSIONS**

This research study focused on the experience of adult blood and marrow transplant (BMT) patients in isolation. Phenomenological methodology was used to understand the true meanings and essences a patient in this type of setting may experience. It appeared evident that being a BMT patient in isolation was more than being a sick patient in the hospital. The procedure caused psychological and physiological stress on both participants in the study. The participants became dependent on staff to survive on the unit.

Even though this information is based on two participants, it reflects the literature that has been done on this population thus far. Art making appeared to be an effective tool for communicating their experience non-verbally. It also was used as a reference tool when they described their experience to the researcher during the open-ended interview.

The data revealed themes that described the participants' experience of being an adult BMT patient in isolation. The themes were as follows:

- Transformation of self
- Feelings of invasion
- Anxieties about protective confinement
- Loss of autonomy and acceptance of dependence

It appeared that being an adult BMT patient in isolation physically and mentally affected both of the participants.

It is important that more research be done on this topic. The information could be used to help medical staff, mental health workers, and art therapists to understand what

the patients are experiencing on the unit. It could also be helpful to other BMT patients in order to understand their experience, by seeing what other patients went through.

## LIST OF REFERENCES

- Andrykowski, M. A. (1994). Psychiatric and Psychosocial Aspects of Bone Marrow Transplantation, *Psychosomatics*, 35(1), 13-24.
- Bar-Sela, G., Atid, L., Danos, S., Gabay, N., and Epelbaum, R. (in press). Art therapy improved depression and influenced fatigue levels in cancer patients on chemotherapy. *Psycho-Oncology*.
- Blood & Marrow Transplant Newsletter (March, 1993) webpage, Relieving Pain – Part I, received August 21, 2007,  
<http://www.bmtinfonet.org/newsletters/issue16/relieving.html>
- Blood & Marrow Transplant Newsletter (May, 1993) webpage, Relieving Pain – Part 2, received August 21, 2007,  
<http://www.bmtinfonet.org/newsletters/issue17/relieving.html>
- Campbell, T. (1999). Feelings of oncology patients about being nursed in protective isolation as a consequence of cancer chemotherapy treatment. *Journal of Advanced Nursing*, 30(2), 439-447.
- Center for International Blood and Marrow Transplant Research (CIBMTR) website, received January 20, 2008, <http://www.cibmtr.org/>.
- Cohen, M. Z., Ley, C., & Tarzian, A. J. (2001). Isolation in blood and marrow transplantation. *Western Journal of Nursing Research*, 23(6), 592-609.
- Collins, C., Upright, C., & Aleksich, J. (1989). Reverse Isolation: What Patients Perceive. *Oncology Nursing Forum*, 16(1), 675-679.

Columbia Presbyterian Medical Center webpage, The Nuts and Bolts of Bone Marrow Transplants, received July 18, 2007,

<http://cpmcnet.columbia.edu/dept/medicine/bonemarrow/bmtinfo.html>

Compton, K., McDonald, J.C., & Stetz, K.M. (1996). Understanding the Caring Relationship During Marrow Transplantation: Family Caregivers and Healthcare Professionals. *Oncology Nursing Forum*, 23(9), 1428-1432.

Gabriel, B., Bromberg, E., Vandenbovenkamp, J., Walka, P., Kornblith, A. B., & Luzzatto, P. (2001). Art Therapy With Adult Bone Marrow Transplant Patients In Isolation: A Pilot Study. *Psycho-Oncology*, 10, 114-123.

Gammon, J. (1999). The psychological consequences of source isolation a review of the literature. *Journal of Clinical Nursing*, 8, 13-21.

Gaskill, D., Henderson, A., & Fraser, M. (1997). Exploring the everyday world of the patient in isolation. *Oncology Nursing Forum*, 24(4), 697-700.

Grazier, S. (1988). The loneliness barrier. *Nursing Times*, 84(41), 44-45.

Greece, M. (2003). Art therapy on a bone marrow transplant unit: the case study of a Vietnam veteran fighting myelofibrosis. *The Arts in Psychotherapy*, 30, 229-238.

Holland, J., Plumb, M., Yates, J., Harris, S., Tuttolomondo, A., Holmes, J., & Holland, J. F. (1977). Psychological response of patients with acute leukemia to germ-free environments. *Cancer* 40(1), 871-879.

Hoodin, F. , Kalbfleisch, K., Thornton, J., & Ratanatharathorn, V. (2004) Psychosocial influences on 305 adults' survival after bone marrow transplantation Depression, smoking, and behavioral self-regulation. *Journal of Psychosomatic Research* , 57(2), 145-154.

Jenkins, P. L., Lester, H., Alexander, J. & Whittaker, J. (1994). A Prospective Study of Psychosocial Morbidity in Adult Bone Marrow Transplant Recipients.

*Psychosomatics*, 35, 361-367.

Kellerman, J. Rigler, D. & Siegel, S. E. (1977) The psychological effects of isolation in protected environments, *American Journal of Psychiatry*, 134(5), 563-565.

Knowles, H. E. (1993). The experience of infectious patients in isolation. *Nursing Times*, 89 (30), 53-56.

Luzzatto, P., & Gabriel, B. (1998). Art psychotherapy. In *Psycho-Oncology*, Holland, J. C., et al. (eds). Oxford University Press: New York, 743-757.

Malchiodi, C. A. (1999). Art therapy, arts medicine, and arts in health care: A vision for collaborations in the next millennium. *International Journal of Arts Medicine (IJAM)*, 6(2), p13, 4p, received January 20, 2008 from Alt Healthwatch.

Medline Plus webpage, Bone marrow transplant, received September 23, 2007,

<http://www.nlm.nih.gov/medlineplus/ency/article/003009.htm>

Molassiotis, A., Van Den Akker, O. B. A., Boughton, B. J. (1997). Perceived social support, family environment and psychosocial recovery in bone marrow transplant long-term survivors. *Social Science & Medicine.*, 44(3), 317-325.

Moustakas, C. E. (1994). *Phenomenological Research Methods*. SAGE Publications: Thousands Oaks, California

Nainis, N., Paice, J. A., Ratner, J., Wirth, J. H., Lai, J., Shott, S. (2006). Relieving symptoms of cancer: Innovative use of art therapy, *Jounral of Pain and Symptom Management*, 31(2), 162-169.

- Naumberg, M. (1987). Dynamically oriented art therapy: It's principles and practice. Chicago: Magnolia Street Publishers.
- Non Hodgkin's Lymphoma Cyberfamily webpage, received April 26, 20008, <http://www.nhlcyberfamily.org/>
- Rosner David, I., & Ilusorio, S. (1995). Tuberculosis: Art therapy with patients in isolation. *Art Therapy: Journal of the American Art Therapy Association*, 12(1), 24-31.
- Rubin, J. A. (2001). Approaches to art therapy: theory and technique. New York: Brunner-Routledge.
- Sasaki, T., Akaho, R., Sakamaki, H., Akiyama, H., Yoshino, M., Hagiya, K., & Atsumi, M. (2000). Mental disturbances during isolation in bone marrow transplant patients with leukemia. *Bone Marrow Transplantation*, 25(3), 315-318.
- Seattle Cancer Care Alliance webpage, Adult Bone Marrow Transplant, received June 27, 2007, <http://www.seattlecca.org/patientsandfamilies/adultCare/transplant/>
- Steeves, R. H. (1992). Patients Who Have Undergone Bone Marrow Transplantation: Their Quest for Meaning. *Oncology Nursing Forum*, 19(6), 899-905.
- Thain , C. W. and Gibbon, B. (1996). An exporatory study of recipients' perceptions of bone marrow transplantation. *Journal of Advanced Nursing*, 23, 528-535.
- The American Art Therapy Association, Inc. webpage, Art Therapy: Definition of the profession retrieved January 19, 2008, <http://www.arttherapy.org/aamembership.html>.
- The Cancer.net webpage, What you need to know about cancer: methods of treatment and their side effects, received August 21, 2007, <http://thecancer.net>.

- The Leukemia & Lymphoma Society. (2002). Blood and marrow stem cell transplantation, Amgen Oncology: White Plains, NY.
- Thomas, E. D. (1987). CA: A Cancer Journal for Clinicians: Bone Marrow Transplantation, American Cancer Society, 37(5), 291-301.
- Thomas Jefferson University Hospital webpage, received July 27, 2007,  
<http://content.jeffersonhospital.org/content.asp?pageid=P00086>
- Twombly, R. (2006). Survivor Recruits Bone Marrow Donors. Retrieved June 22, 2007,  
 from <http://www.cancerwise.org>.
- University of Utah Health Sciences Center webpage, Hematology & Blood Disorders:  
 Bone marrow transplant, retrieved April 26, 2008,  
<http://healthcare.utah.edu/healthinfo/pediatric/Hemat/bonetrans.htm>
- Wadeson, H. (1995). The dynamics of art psychotherapy. New York: John Wiley & Sons, Inc.
- Wilkins, E. G. L., Ellis, M. E., Dunbar, E. M. & Gibbs, A. (1987) Does isolation of patients with infections induce mental illness? *Journal of Infection*, 17, 43-47.
- Zerbe, M.B., Parkerson, S. G., Spitzer, T. (1994) Laminar air flow versus reverse isolation: nurses' assessment of moods, behaviors, and activity levels in patients receiving bone marrow transplants. *Oncology Nursing Forum*, 21(3), 565-568.

## APPENDIX 1

# Thomas Jefferson University

## Volunteers Needed!

To participate in Drexel University graduate student research

Research Study Title: Understanding the lived experience of adult blood and marrow transplant patients in isolation via an art making task and verbal interview

Volunteers will be asked to partake in the following: an informed consent meeting (15-20 minutes), art-making (20-30 minutes) and an open-ended interview (30-40 minutes)

**\$25 Gift certificate will be rewarded upon completion of the study**

### **If you are...**

- An adult BMT patient in isolation at Jefferson
- Able and willing to participate in art-making directive and in-depth interview
- In isolation for at least 10 days
- Do not have history of inpatient hospitalization for a psychiatric disorder or drug and alcohol abuse prior to BMT
- Between the ages of 18-70

Then please ask your nurse to contact  
Carrie Adcock at (610) 405-8431 by \_\_\_\_\_.

Your time and effort are greatly appreciated!

\*This study may cause a patient to feel upset or discomfort due to describing their lived experience as an adult BMT patient in isolation.



## APPENDIX 2

## Consent Form

**Thomas Jefferson University**  
**Informed Consent Document for Human Subjects Research**

**Department:** Blood and Marrow Transplant Unit

**Co-Principal Investigator(s):** Joanne Filicko-Ohara, MD,  
Dr. Elizabeth Hartzell, Ph. D., ATR-BC, LPC **Telephone:** 5-9504

**Co-Investigator(s):** Matthew Carabasi, MD, Caroline Peterson, MA, ATR-BC, LPC &  
Carrie Adcock, BA **Telephone:** 610-405-8431

**Medical Title:** Understanding the experience of adult blood and marrow transplant patients in isolation via an art making task and verbal interview

### **What Is an Informed Consent?**

You are being asked to take part in a medical research study. Before you can make a knowledgeable decision about whether to participate, you should understand the possible risks and benefits related to this study. This process of learning and thinking about a study before you make a decision is known as *informed consent* and includes:

- Receiving detailed information about this research study;
- Being asked to read, sign and date this consent form, once you understand the study and have decided to participate. If you don't understand something about the study or if you have questions, you should ask for an explanation before you sign this form;
- Being given a copy of your signed and dated consent form to keep for your own records.

### **Introduction and Study Purpose**

Following a blood and marrow stem cell transplant (BMT), patients receiving this procedure have to be placed in isolation for 4-6 weeks (sometimes months). During the isolation period, a BMT patient may experience psychological and/or physiological strain. There has been little research on the experience of adult stem cell transplant patients in isolation. Given the nature of isolation there may not be adequate words to describe the experience. The use of non-verbal creative expression (art), may offer a means for patients to better understand their experience, begin to organize it and find the right words emerge from it. The purpose of this study is to understand the experience of a patient in isolation through art and interview. The information gathered non-verbally (through the art-making production) and verbally (through an in-depth interview) will help in understanding the experience of a bone marrow transplant patient in isolation.

## **Procedures/Treatment**

If you agree to participate in this study, you will be one of four adult stem cell transplant patients in isolation on the blood and marrow transplant (BMT) unit will participate in this study, involving an art making task and an open-ended interview. This study will last between 90 and 120 minutes for one session in your hospital room. However, depending on your health, the session may take place as two separate meetings. The interview will be an open-ended interview concentrating on the question, what is the experience of having your disease and living in isolation as a part of your treatment? Each interview will be tape-recorded and transcribed. After transcription, the tapes will be destroyed for confidentiality purposes. The researcher will then look for common themes in each interview.

## **Risks/Discomforts**

The risk of participation in this study is minimal. This study may make you feel upset or discomforted due to describing your experience as an adult stem cell patient in isolation. If you feel upset or discomfort during the study, please inform the researcher right away. Medical staff will be on site if necessary. You may withdraw from this study at any time.

## **Alternative Treatments**

Your alternative is not to participate in this study.

## **Confidentiality**

There are federal regulations about protecting information about you. This information is called “protected health information”(PHI). PHI includes things that identify you personally like your name, address and social security number, etc., or any medical or mental health record, or test result, such as an X-ray, that may have this sort of information on it. According to federal and state regulations, you may see your health information at any time. However, in a research study, you may not see the health information related to the research until after the research is completed unless the study doctor decides otherwise.

By signing this consent form, you are allowing the research team to have access to your PHI. The research team includes the investigators listed on this consent form and other personnel involved in this specific study. Your PHI will also be shared, as necessary, with the University’s Division of Human Subjects Protections and the Institutional Review Board (a University committee that reviews, approves and monitors research involving human subjects). You are also allowing the research team to share your PHI with your health insurance company (if necessary for billing for standard medical care) and other people or groups as follows:

Drexel Hahnemann Creative Arts in Therapy Program

All of the above entities are obligated by law to protect your PHI.

The following information will be provided to the study sponsor and other entities noted above.

*Study data for analysis: none.*

Demographic data: age, gender, nationality, type of disease

**Other: artwork and transcriptions from audiotapes**

Your PHI will be used/disclosed

☐ until the end of the research study

☒ indefinitely

You may quit the study and revoke permission to use and share your PHI at any time by contacting the principal investigator, in writing, at:

Joanne Filicko-Ohara, MD  
801 Sheridan Bldg, 125 South 9th Street  
Philadelphia, PA 19107

If you quit the study further collection of your PHI will be stopped, but PHI that has already been collected may still be used.

The information from this study may be published in scientific journals or presented at scientific meetings but you will not be personally identified in these publications and presentations.

### **Benefits to Subject**

You may or may not benefit directly from your participation in this study. However, although you may not benefit directly from this research, there may be a benefit to society, in general, from the knowledge gained in connection with your participation in this study. Any information obtained from this research study, and which may be important to your health or disease progression, will be shared with you.

### **Payment**

You will be given a \$25 gift certificate to *Barnes & Noble*.

### **Contact Information**

If you have any questions or concerns about this research, **or if you experience a research-related injury**, call the Principal Investigator, Dr Joanne Filicko-Ohara at

Pager number 5-9504. Should you have any questions regarding your rights as a research participant, you may contact Thomas Jefferson University's Institutional Review Board, which is concerned with the protection of participants in research studies, at Telephone: (215) 503-8966.

### **Voluntary Consent and Subject Withdrawal**

You voluntarily consent to be in this research study. You have been told what being in this study will involve, including the possible risks and benefits. Your participation in this research project may be terminated by the researcher without your consent if you are not benefiting from the treatment or procedure, or if it is decided that being in the study is not appropriate for you. You may also be taken out of the study at any time for any reason(s) that the researcher feels is appropriate.

You may refuse to participate in this investigation or withdraw your consent and discontinue participation in this study without affecting your ability to receive medical care at Thomas Jefferson University.

If you withdraw from this study, there will be no consequence.

**Non-Waiver of Legal Rights Statement**

By your agreement to participate in this study, and by signing this consent form, you are not waiving any of your legal rights.

**In order to be in this research study, you must sign this consent form.**

**You affirm that you have read this consent form. You have been told that you will receive a copy.**

**Signatures:**

\_\_\_\_\_(Date)  
Your Name (*please print or type*)

\_\_\_\_\_(Date)  
Your Signature

\_\_\_\_\_(Date)  
Name of Person Conducting Consent Interview

\_\_\_\_\_(Date)  
Signature of Person Conducting Consent Interview

\_\_\_\_\_(Date)  
Signature of Principal Investigator or  
Co-Investigator

## APPENDIX 3

## Transcribed Interviews

*Kate (Participant 1)*

R = Researcher

P = Participant

R: Okay, so what is the lived experience of an adult bone marrow transplant in isolation?

P: The what?

R: What is the experience...

P: Well...its not fun. There is a lot of people that think it is. But, when you come in here,

they tell you, you gonna be in here for 6-8 weeks...and you trust you. You trust

you that you are going to be in here for 6-8 weeks... they're not letting you go

home unless you feel good. If you feel good, they let you go home. If you don't

feel good, you're stay'n right here. 'Cause if you can't change you... If you're

not feeling up to par, they're not going to send you home...you'll come back.

Umm... So...so...it's not easy, it's hard...everybody may think it might be easy,

but it's not...especially when you're getting somebody else's cells in your body.

R: Uh hmm...that experience has been...

P: Yeah...It's been like a rocky road...

R: Yeah?

P: ...'Cause you don't know if your body is going to accept it or not. And um...

R: What's that like?

P: It's like a battle. Your cells are trying to accept somebody else's cells when you're not 100%. I don't know what 100% is like because I've never had 100%.

R: Okay. Alright...so how did you depict your experience in your artwork associations with the art materials?

P: How did I depict my artwork with my art..

R: How did you depict your experience in your artwork associations with the art materials?

P: My...my art...my artwork and the materials I used...they're pretty good.

R: Yeah?

P: Yeah..I mean you can only...you can't use real real real real real light colors because then you won't be able to see what the picture is..what the picture is saying.

R: Uh hmm...

P: ...So you got to use some dark colors.

R: So you used the d..dark colors...

P: So you could see what the uh...the stuff is.

R: Yeah...okay. So do you feel like...your artwork...do you feel like it helped explain it? Can you explain it a little?

P: Yeah...you got a desk....you got a bed...chair...you got the window...you got the stuff hanging from the wall...

R: Uh hmm...

P: ...You got the uhh...nurse call button...your tv button...

R: Oh, is that what this is?

P: Uh hmm...

R:...Is this the nurse's call button?

P: Uh hmm...you got the bed...you got the wheels under the bed...

R: Oh, okay...I see what you did. So, these are the wheels?

P: Uh hmm...

R: And what's this?

P: Closet door...

R: ...And how about this?

P: That's one of them bags hanging off of the wall.

R: One of the...

P: ...bags hanging off the wall.

R: ...hanging off the wall...Well, that does...that does look like your room. You got everything. You got the blinds...the chair...Do you think doing the art work...making the artwork helped explain your experience any more?

P: Well...this artwork couldn't explain any experience...I don't know how many pictures it would to explain the experience... 'cause sometime... you can't...sometimes you can't draw experience...sometimes you gotta just tell it...

R: Hmm..

P: I couldn't draw everything that happened in there.

R: Is there stuff that you would add to it?

P: Yeah...sometimes you get sick and throw up. Sometimes..sometimes you have a bad reaction to something...And...you start spaz'n out and you don't know what to do...and all of the nurses come running in and...



R: What's that like?

P: What...when all them nurses come running in?

R: ...That whole spaz'n out and they don't know what's going on...

P: Well..for me...for me it's scary because I've never been sick before. For somebody, else it might just be like...they want them to hurry up and get it under control...they ask me a lot of questions because like I said, I've never been sick before. They ask me a million questions.

R: Yeah?

P: Yeah...

R: So the experience has been..

P: New.

R: New?

P: Yeah. 'Cause like I've been saying, I have never been sick before in my life. So, the experience has been new.

R: Is there any other words you would to describe it?

P: I mean we have fun times too. They try to make it...well..for me...I don't know about nobody else...they try to make it...you know...as uhh...pleasant as possible... 'cause they know you away from home and you want to go home...But...you can't 'cause you're sick.

R: Yeah...what's that like?

P: It's like, you want to go home and you can't go home...and there ain't nothing you can do about it. You have to be a big girl. Yup.

R: So, being a "big girl," what does that mean?

P: It can mean, bare with it. It can't be that bad. I mean you're still here, you're still  
breath'n...you got people to talk to.

R: Hmm..well, thank you very much. I think you did a great job.

P: You're welcome.

R: That was great.

*Connie (Participant 2)*

R = Researcher

P = Participant

R: So, what is your lived experience of being an adult blood and marrow transplant unit  
in isolation?

P: Today, which is only...in isolation...which has...it's not been a month yet...it's been  
uhh..it's...in the beginning it was...you know...uhh.. it was exciting going into the  
transplant.

R: Hmm..

P: Knowing that that was the next...You know...You go into the chemotherapy..

R: Yeah.

P: ...before...was..I knew it was going to be hard. But..uhh..getting the new cells,  
means you have a new birthday. You know..

R: Yeah..

P: So, uhh.. it was my only option... So...and everything was good to me until... after...I  
mean...I'm talk'n physically, not...

R: Yeah

P: ...not surroundings wise here...Um..about..until like three days ago til now..four days ago...since the last time I talked to you.

R: Yeah.

P: And I..I..It took over my body...with diarrhea and..and uh...nausea...and I couldn't even get out of bed one day...

R: Hmm..

P: It's debilitating...mentally...debilitating.

R: Yeah. So, sounds like mentally and physically.

P: Yeah..yeah. But... I get through every day because there are two things I... I believe. I believe the Lord is going to heal me with this...I'm a religious person...

R: Uh hmm..

P: ...and I believe in my family because I uh...Would be too...

R: Yeah...

P: ...would be too..You know I don't have doubts...I just get down...Just like everybody else gets down.

R: Yeah.

P: Have good days, bad days.

R: Yeah.

P: But the...the unit here...has been excellent...I...I didn't expect and...to be honest with you, I thought I made a wrong decision coming to [the hospital].

R: Yeah?

P: ...for the kind of Hodgkin's I have...'cause they don't...uhh they don't really...they don't have...they didn't have a history of doing a lot of Hodgkin's Lymphoma.

R: Oh yeah?

P: Yeah, I mean they do transplants...but they don't...people on the floor don't have Hodgkin's lymphoma...and the kind of Hodgkin's I have.

R: Uh huh..

P: So it's...it's uh...I...when you look at statistics, the statistics tell you to go to bigger hospitals. Ann Arbor Institute...umm...Sloan Ketterington...

R: Uh hmm...

P: MP Anderson is a big one...that a lot of people go to.

R: Hmm.

P: But I just made up my mind...and just...the best thing for me. And the minute I got here... I sensed it was the right place.

R: Huh.

P: Like...it's cause of staff.

R: Yeah.

P: They're wonderful nurses.

R: Yeah.

P: I mean really wonderful nurses. Uh...they'll go out of your way. Sarah\* went down bought me a pack of lifesavers off of the street yesterday. And...and...that's a lot for them to go off this floor...they don't ....they don't like to go off the floor...but... they have to scrub all over again...they don't... they don't like to go to lunch. They order in

all the time, you know...and when the nurses...like you know...you know...have 5 minutes to talk to ya, they do. And they made it a lot...a lot nicer.

R: Aw. That's nice.

P: Yeah. So it's just getting through the hard parts, right now.

R: Okay. Well...well how did you depict your experience in your...in your artwork?  
Can you tell me about your artwork?

P: Basically...I just wrote different comments on a chart.

R: Okay.

P: Great stuff...Um...when the bone transplant began. And I mentioned..uh...Ke..

R: ..Kelly\*...

P: Kelly\*...the day of the transplant, she pushed these big needles in my arm.

R: Ohh.

P: ...and she's so little. She's like 80 pounds....And she could...I was watching her.  
She was so intense. And I...and she...her hand was turning purple.

R: Hmm..

P: You have to do it at a certain time sequence. Once they're unfrozen, they have to...I think like... there is like 8 minutes they have to be uh...out.

R: Yeah, yeah. Yeah, yeah...

P: And uh, she was...she was gone and we were having trouble with my port the day before...the day before that...and...and uh she really did all she could to get that going.  
Just different comments I made about the...you know you have happy days. Things you think about. You know...I think about work...you know, what's going on there...while I'm here.

R: Yeah.

P: Yeah.

R: So, you're artwork really does depict your experience daily, it looks like...

P: Yeah....and at the end I wrote who I miss the most...

R: Ohh...

P: ...sleeping in my bed!

R: Oh, is that what that means?

P: Yeah.

R: So you...so your experience here is really...you do...you miss your family it looks like.

P: Because um...we're very close...

R: Are you?

P: I'm not married. I live with my 81-year-old mom.

R: Yeah.

P: I'm sorry I'm crying.

R: No...that's okay. This is a difficult subject...to talk about it.

P: I...I don't have to worry about her...for her needs...because my brother is taking care of her with my sister-in-law...and they're just like me...taking care of her. But, she misses me.

R: Yeah.

P: And she worries about me... her at this time...she's not in great health...that's why I worry.

R: 'Cause your mom is not in great health...

P: Like she...she's older...and she trip and fallin'...

R: Yeah.

P: She ..she can't...um...she can't walk without a walker. When you see her...she would...you would think she's just fine. She's a nervous..she has high blood pressure. She had breast cancer... two months after I was diagnosed with this, she was diagnosed with breast cancer.

R: Oh, wow.

P: Oh, it was the most devastating thing.

R: When was that?

P: In uh...in November of '06.

R: Okay.

P: So we had to deal with that, while I was doing this. So like....I got to...we had to divide up shifts.. I had to take care of..you know...of all my appointments...And you know Bob\* would take care of uh...of uh.. I mean, Jane\*, my sister-in-law, would take care of my mom.

R: Yeah.

P: And she had to go 6...she had a mysec...mysectomy done...and it was cancerous...so they wanted to do 6 and a half weeks of radiation.

R: Hmm.

P: And they did it. And...and it's gone now. So she's cancer free with that but it takes a lot out of you when you're 80 something like that.

R: Yeah.

P: She'll be 82. So that's...that's yeah...that bothers me when she's...you know...when she's home alone. My nieces and nephews stay there during the night with her but...you know...she misses me...my company.

R: Yeah, and... so that adds to your experience here.

P: Yeah. 'Cause I'm worrying about her now.

R: So, it sounds like it's really difficult to be away from her.

P: Yeah, 'cause I'm close to her. And we've gotten closer since I've been sicker...sick.

R: Huh.

P: Yeah, well when I was at work...normal everyday...back uh... two years ago, she wouldn't see me from you know... six o'clock in the morning til seven at night...it was different. You know she knew I was going home...and I'd come home...we would watch a couple of television shows..

R: Yeah.

P: But this is...I...ever since I have been sick and have been home a lot...she's like...grown...and I can see her... and my brother sees it too in her...her health...it has taken a toll on her...you know...the emotional stress...

R: Yeah.

P: Yeah and he sees how much she can take...her breathing heavy...and...you know...we get nervous for her...It will be okay.

R: Hmm. Well, do you think that any of the issues that you just talked about came out because you did the artwork? Do you think that you did...that it came out?

P: ...Yeah.

R: Yeah.



P: ...Yeah, I think so...it makes you...you know....It just makes you want to write everything it down.

R: That's kind of what you did...

P: Yeah.

R: ...you wrote it all down.

P: Yeah...I didn't know what to do...I didn't feel like writing flowers and collage and drew a picture and that interpreted them. If you gave me a week and (laughing)...

R: (laughing)

P: Maybe I could have then...I'm really not that artistic.

R: No...

P: So...I wouldn't.

R: No, you did perfect. You did really well. That was awesome...That's good.

P: Alright